EXAMPLES OF PERSON-CENTERED PLANNING

Annotated table of contents

Chapter 4

   Provided by Capitol People First and Protection & Advocacy, Inc.
   Part of the Peer Advocacy Project, this guideline to the IPP
   (Individual Program Plan) is direct and in understandable language.
   It describes the Lanterman Act and the law, rights, what an IPP is
   and why it is important, the IPP meeting and how to prepare for it,
   the appeal process and an IPP planner. This is a consumer-driven
   and-directed document.

   Alien, Shea & Associates developed this guide for Harbor Regional
   Center. It is directed toward training regional center personnel and
   provides tips on the person-centered planning process. It is also
   universally useful for consumers, families, and providers of service.
   The guide includes what person-centered planning is all about,
   families of young children, families of students, transitions and adult
   life. Samples of interviews and plans are included. There is also a
   section on circles of support.

PERSONAL PROFILE AND POSITIVE FUTURES PLAN

Date of Report:

Locator:

IDENTIFYING INFORMATION

Name:

Date of Birth:

ID#:

Address:

Referral Source:

CPC:

Submitted by:

Cheryl Stroll, M.A./Stacy Daniels, M.A.

Program Manager, SCIP

Social/Community Integration and Participation

Los Angeles/Ventura

Name_____

Personal Profile and Positive Futures Plan

A meeting was held on <u>date</u> using person-centered planning processes and group graphs to generate a personal profile. A second meeting was held on <u>date</u> to develop a futures plan. The following information is a transcription of the wall charts generated in those meetings.

Name of Participant	First Meeting	Second Meeting	Title	Goals or Incentives for meetings
Name	Date	Date	Title	• First goal

Name:_____ Personal Profile and
Date:_____ Positive Futures Plan

HISTORY
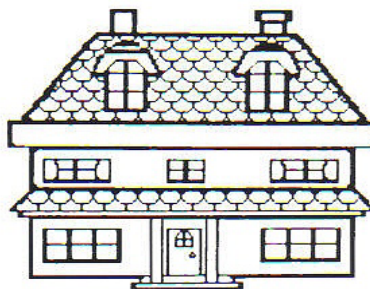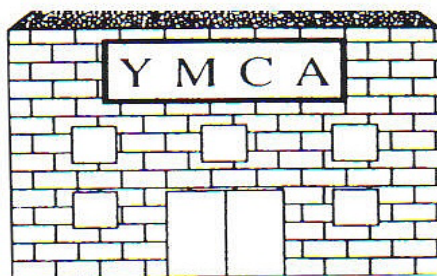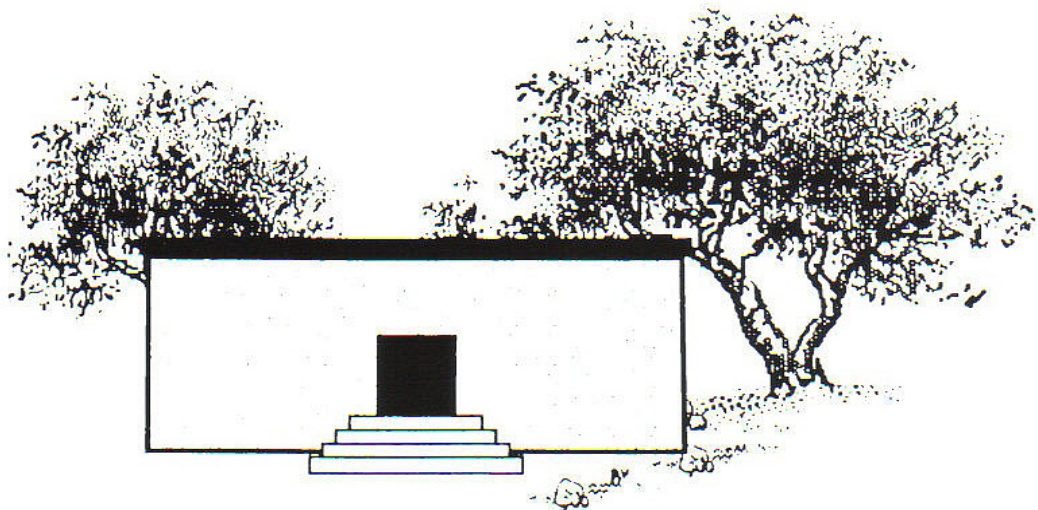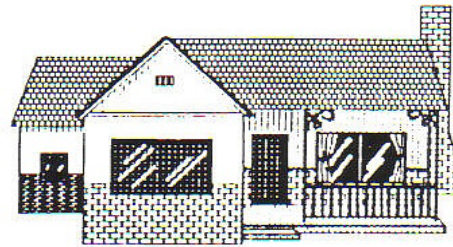
Name:_____ Personal Profile and
Date:_____ Positive Futures Plan

CURRENT SITUATION

Community

Home

Day Program

Y M C A
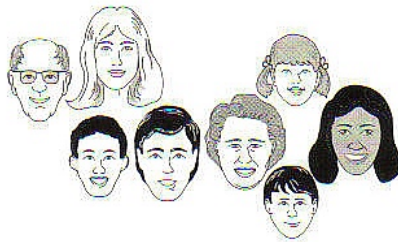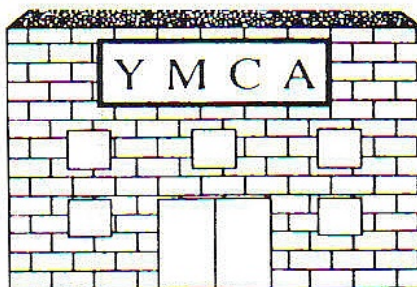
Transportation
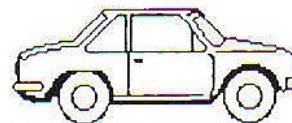
Name:_____ Personal Profile and
Date:_____ Positive Futures Plan

PEOPLE IN <u>NAME?</u>'S LIFE

Service Providers
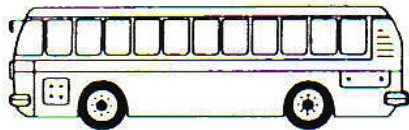
Family

Community

Friends
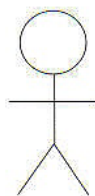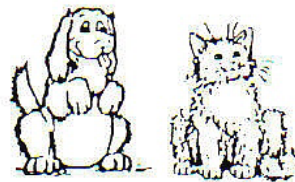
Name:_____ Personal Profile and
Date:_____ Positive Futures Plan

HEALTH		
Indicators of Good Health	**Physical Limitations**	**Themes and Recommendations**
Item	**Item**	**Item**

Name:_____ Personal Profile and

Date:_____ Positive Futures Plan

RESPECT AND DIGNITY		
Characteristics Which Gain Respect	**Characteristics Which Lose Respect**	**Themes**
Item	**Item**	**Item**

Name:_____ Personal Profile and

Date:_____ Positive Futures Plan

THINGS THAT WORK AND THINGS THAT DON'T WORK		
People, Settings and Activities Which Create Interest, Happiness and Engagement	**People, Settings and Activities Which Create Upset, Boredom or Escape**	**Themes**
Item	**Item**	**Item**

Name:_____ Personal Profile and
Date:_____ Positive Futures Plan

CHOICES		
Choices Made by Name	**Choices Made by Others**	**Themes**
Item	**Item**	**Item**

Chapter 4

Name:_____ Personal Profile and
Date:_____ Positive Futures Plan

A VISON OF THE FUTURE FOR <u>NAME?</u>

Home   Work

Characteristics
- text

- text

Support Staff
- text

Pay
- text

Neighborhood
- text

Community

Recreation/Leisure
- text

Transportation
- text

Services
- text

Classes
- text

Name:_____ Personal Profile and
Date:_____ Positive Futures Plan

TASKS		
Task	**Person**	**Date**
Item	Item	Item

_____ Personal Profile and Positive Futures Plan First Meeting_____ Second Meeting_____	☐	☐	A meeting was held on

Name of Participant			Title	Goals or Incentives for Meetings
				*
				*
				*
				*
				*
				*
				*
				*
				*
				*
				*
				*
				*
				*
				*

HISTORY	**CURRENT SITUATION**
	Home Work Transportation Community

Date: _____

PEOPLE IN <u>NAME'S?</u> LIFE

Service Providers   Family
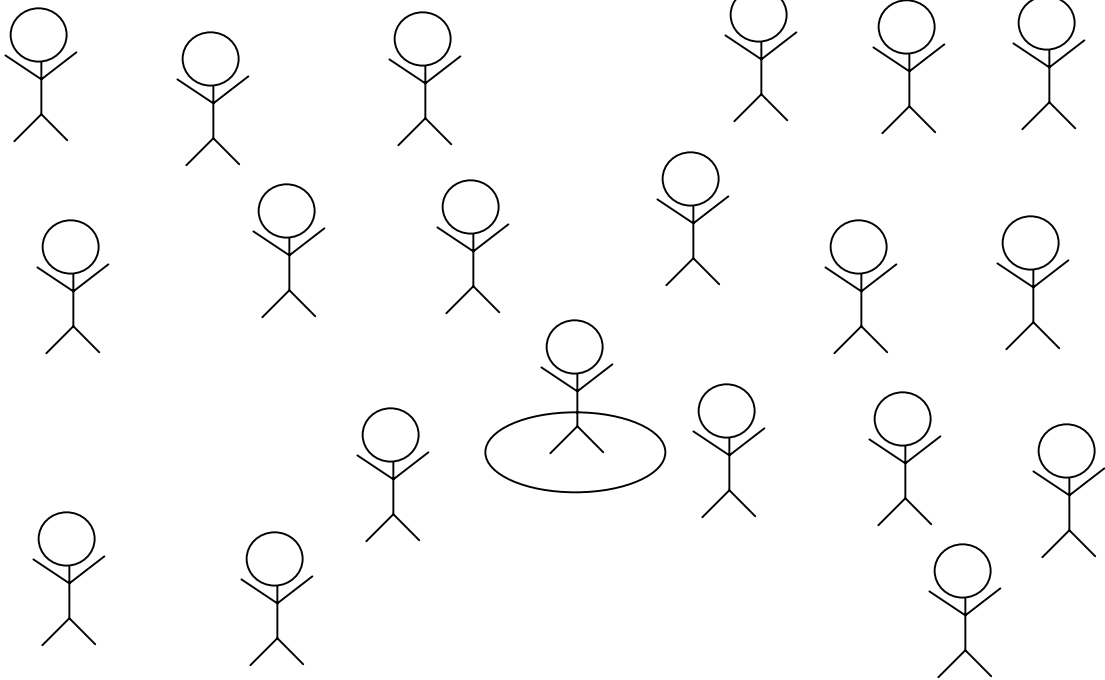
Community Supports   Friends

Date:_____

HEALTH

Indicators of Good Health	Physical Limitations	Themes and Recommendations
*	*	*
*	*	*
*	*	*
*	*	*
*	*	*
*	*	*
*	*	*
*	*	*
*	*	*
*	*	*
*	*	*
*	*	*
*	*	*

Date:_____

RESPECT AND DIGNITY

Characteristics Which Gain Respect	Characteristics Which Lose Respect	Themes
*	*	*
*	*	*
*	*	*
*	*	*
*	*	*
*	*	*
*	*	*
*	*	*
*	*	*
*	*	*
*	*	*
*	*	*
*	*	*

Date:_____

THINGS THAT WORK AND THINGS THAT DON'T WORK

Characteristics Which Gain Respect	Characteristics Which Lose Respect	Themes
*	*	*
*	*	*
*	*	*
*	*	*
*	*	*
*	*	*
*	*	*
*	*	*
*	*	*
*	*	*
*	*	*
*	*	*
*	*	*

Date:_____

CHOICES

Choices Made by Name?	Choices Made by Others	Themes*	* Recommendations
*	*	*	*
*	*	*	*
*	*	*	*
*	*	*	*
*	*	*	*
*	*	*	*
*	*	*	*
*	*	*	*
*	*	*	*
*	*	*	*
*	*	*	*
*	*	*	*
*	*	*	*

Date: _____

A VISION OF THE FUTURE

Neighborhood

Home

Support Staff

Work
Type of Work
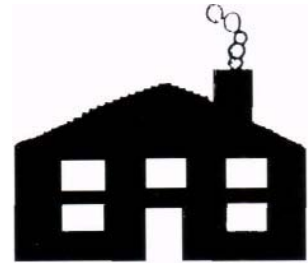
Day

Characteristics of Work Place

Supports

Community

Recreation/Leisure

Transportation

Shopping

Community Participation

Services

Supports

Date:_____

TASKS		
Task	**Person**	**Date**
1.		
2.		
3.		
4.		
5.		
6.		
7.		
8.		
9.		
10.		
11.		
12.		
13.		
14.		
15.		

MY LIFE . . .
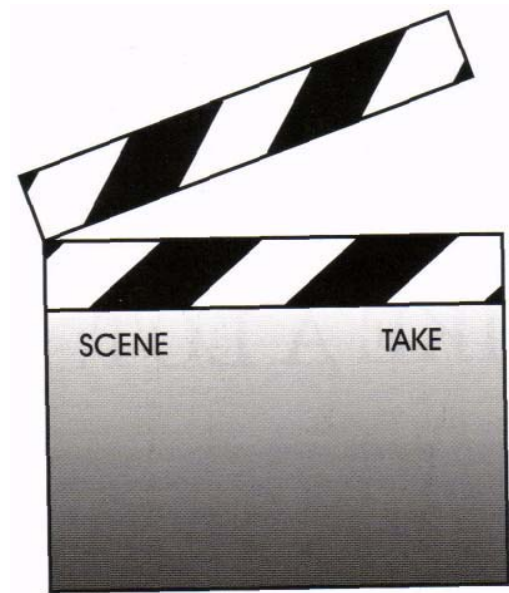
BY

Who is ?

Things I ♥ Love

Things I LIKE A LOT:

Things I DON'T LIKE:

Things I *REALLY* DON'T LIKE:
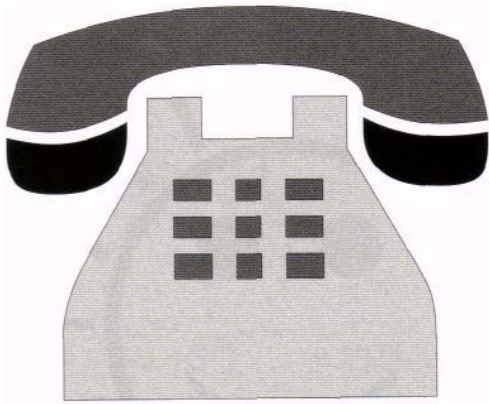
These people are important to me. I want to invite them to my futures planning meeting:

Some things make me
(List)

And sometimes I get sad.
(List)

These are my greatest FEARS!

These are NEW things I want to do and learn:
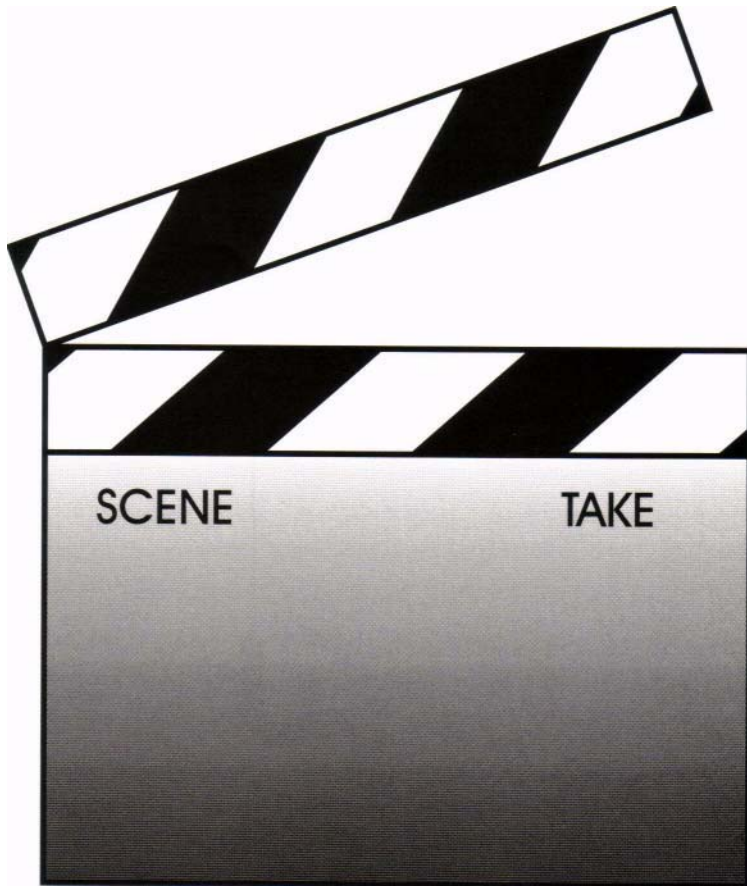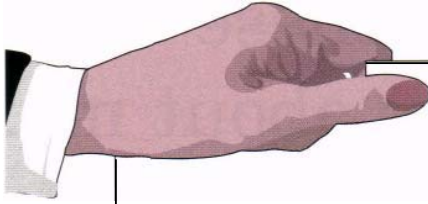
I currently get these services:

✓

✓

✓

✓

✓
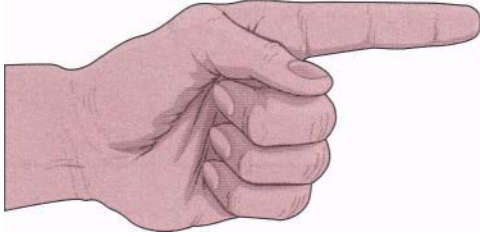
People at work think these things about me
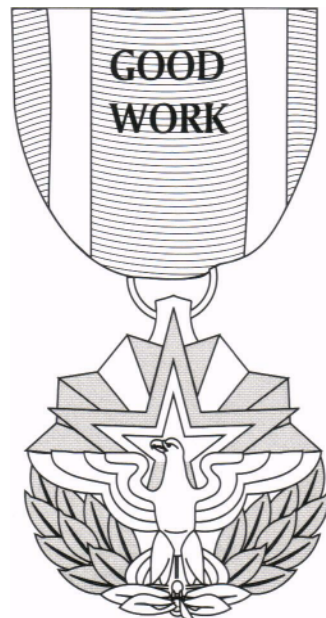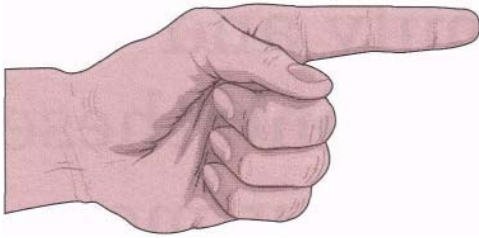
People at home think these things about me:
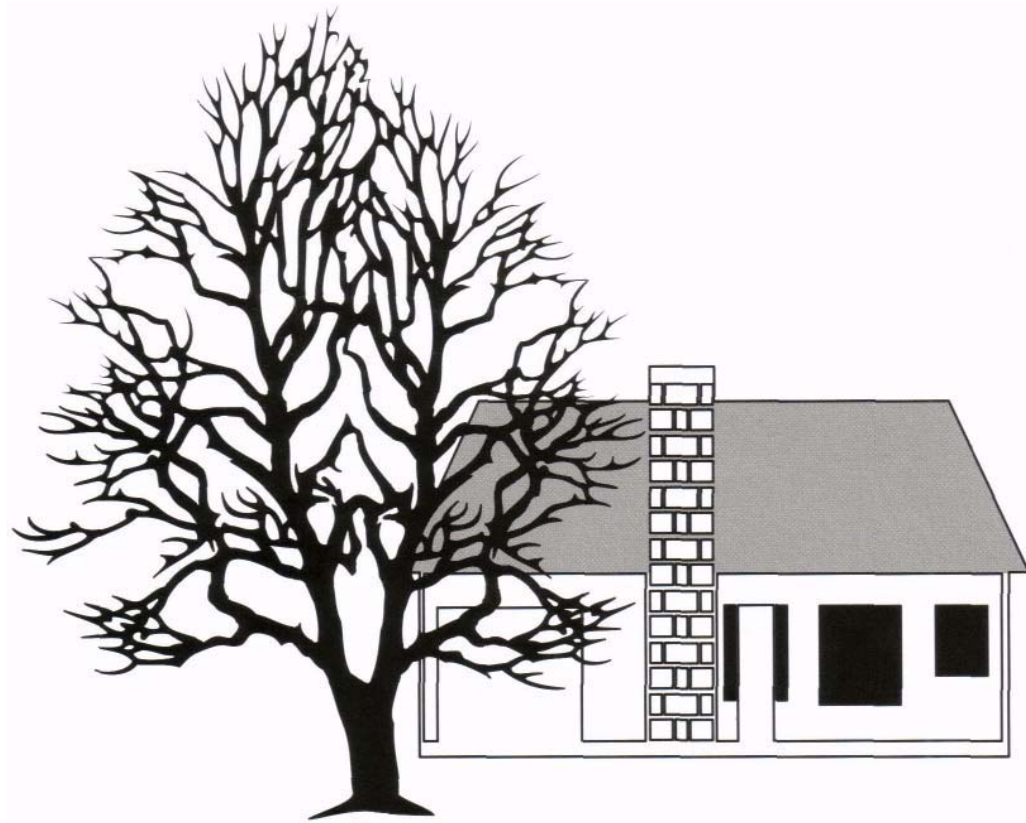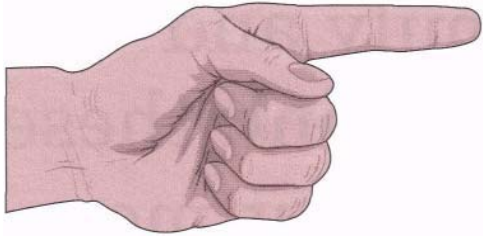
My family and friends think these things about me:
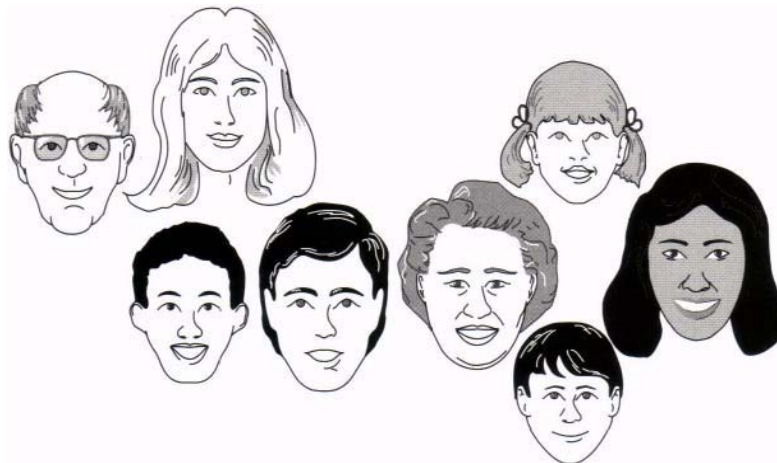
These are the best things

about my JOB:

About my HOME:
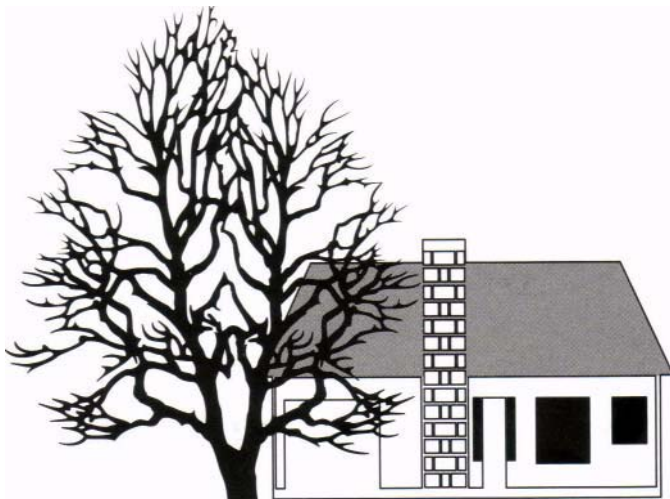
The things I most often need help with at home and work are:
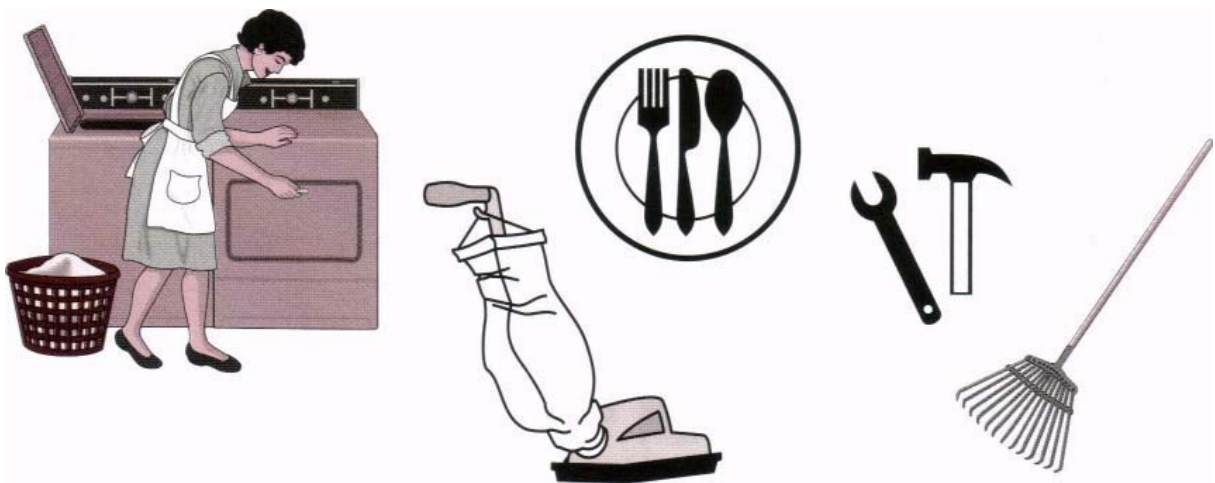
My perfect job would be . . .
(explain why)

My perfect home would be .
(explain why)
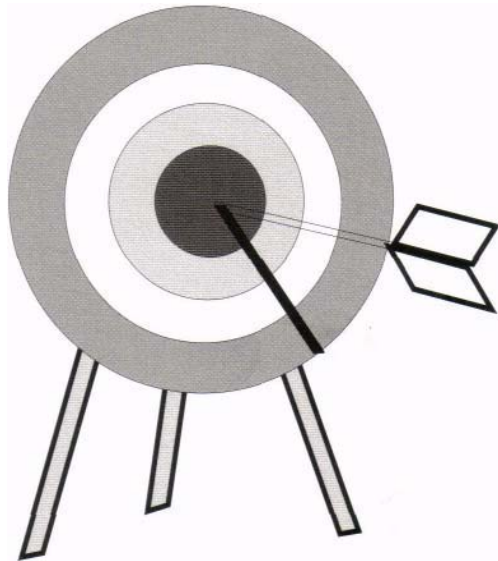
My health needs:

I need this much money to live and this is where it comes from:

Places to go . . .
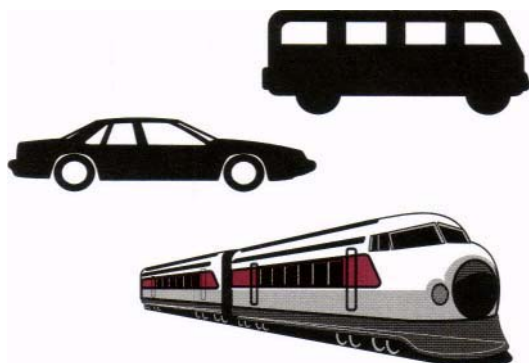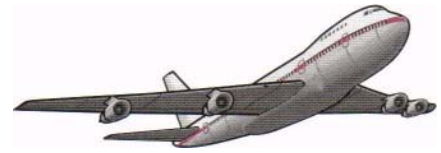
If my world were perfect, this is what I'd be doing:

At Home:

At Work:

In the Community:

With My Friends:

FINDING A WAY TOWARD EVERYDAY LIVES

The Contribution of

Person-Centered Planning

John O'Brien and Herbert Lovett

Pennsylvania Office of Mental Retardation

Harrisburg, Pennsylvania

Chapter 4

Since the publication of *Everyday Lives,* "the vision for our future," we have come to realize that each person has his or her own personal image of a desirable future. And so we have been looking for ways to discover what each person's image of a desirable future is and for the means to make that image a reality.

Person-centered planning in its many and varied forms, if approached in a thoughtful, sincere, and indeed, a moral manner, can help us. It can help us to listen, to understand, and most importantly, to act.

This publication, so thoughtfully prepared by John O'Brien and Herb Lovett, describes the foundation of person-centered planning and its potential for creating a better future for people and for influencing change. It also addresses controversies and fears associated with this new approach.

While person-centered planning is regarded as a new idea, it springs from our basic humanity, our eternal capacity for love, and our common desire to create a world that is safe and welcoming for every one of us.

With the insight, advice and cautions of the people whose thoughts are contained in this booklet, let us move forward with our efforts to bring to reality the vision in *Everyday Lives.*

Nancy R. Thaler
Deputy Secretary for Mental Retardation
February, 1993

Chapter 4

CONTENTS

FINDING A WAY TOWARD EVERYDAY LIVES

Person-Centered Planning can invite, align, and direct shared efforts to create . . .

Work on understanding the community role & contribution of people with disabilities

. . . new community roles and relationships for people with disabilities and their friends and assistants

Person-Centered Planning

Redesign of human service culture, mission, & structure
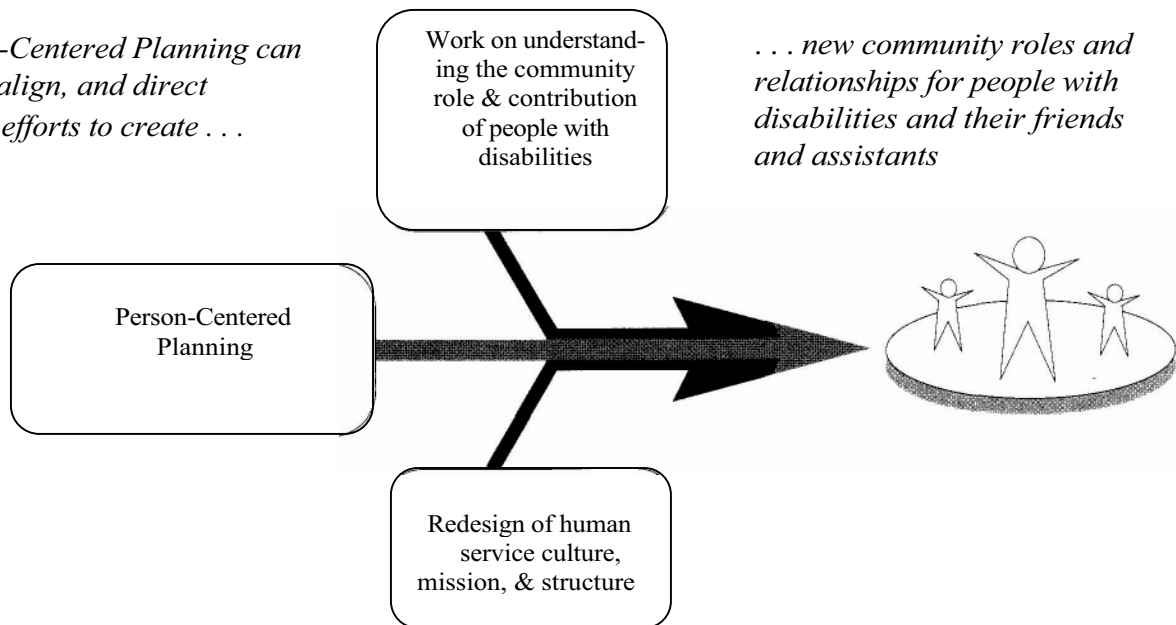
FOUNDATIONS OF PERSON-CENTERED PLANNING

The term, person-centered planning, refers to a family of approaches to organizing and guiding community change in alliance with people with disabilities and their families and friends.

Person-Centered Planning

Individual Service Design

Personal Futures Planning

Essential Lifestyle Planning

Lifestyle Planning

MAPS
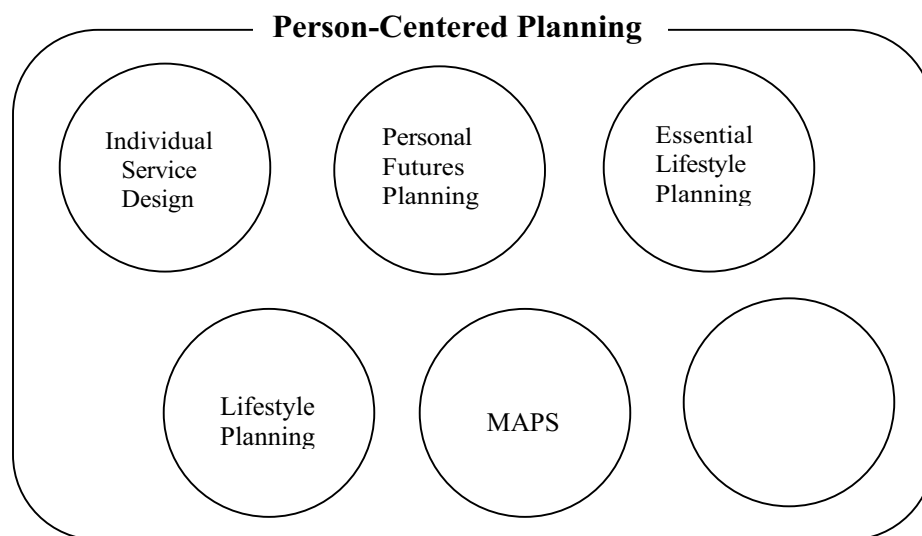
Each approach to person-centered planning has distinctive practices, but all share a common foundation of beliefs:

- The person at the focus of planning, and those who love the person, are the primary authorities on the person's life direction. The essential questions are, *Who is this person?* and *What community opportunities will enable this person to pursue his or her interests in a positive way?*

  - Knowledge gained from close, respectful, continuing relationships with the focus person is crucial in answering these questions.

  - Information gained from technical assessments of the person can be helpful, but only in the context of a knowledgeable account of a person's history and desired future. Subordinating professional-technical information to personal knowledge turns the typical agency decision-making process on its head.

- The purpose of person-centered planning is learning through shared action. People who engage in person-centered planning may produce documentation of their meetings, proposals, contract specifications, or budgets. These are only footprints: the path is made by people walking together.

  - The focus person and those who know the person best may be uncertain about what is possible or desirable for the person. One function of person-centered planning is to decrease such uncertainty by encouraging people to try new things together and to learn from them.

  - The focus person and others the focus person relies on may disagree about what is possible or desirable for the person. Disagreements may be explicit and verbal or they may surface in the behavior of all of the people involved. One function of person-centered planning is to provide a forum for negotiating such conflicts.

- Person-centered planning aims to change common patterns of community life. Segregation and congregation of people with disabilities are common. Devaluing stereotypes and inappropriately low expectations are common. Denial of opportunity is common. These negative patterns do not necessarily signify mean-spiritedness so much as undesirable habit. If invited to assist a person to pursue a desirable future, some people may remain closed and rejecting, but others will respond generously, based on their sense of justice. Person-centered planning stimulates community hospitality and enlists community members in assisting focus people to define and to work toward a desirable future.

- In order to support the kinds of community changes necessary to improve people's chances for a desirable future, virtually all existing human service policies and agencies will have to change the ways they regard people, the ways they relate to communities, the ways they spend money, the ways they define staff roles and responsibilities, and the ways they exercise authority. Person-centered planning requires collaborative action and fundamentally challenges practices that separate people and perpetuate controlling relationships.

- Honest person-centered planning can only come from respect for the dignity and completeness of the focus person. This respect leads those involved in person-centered planning to work for . . .

. . . equal, non-coercive relationships with the people they plan with

. . . appreciation and celebration of each person's uniqueness, and constructive ways to understand one another's challenges and failings

. . . effective ways to communicate the importance of respect and equality to others involved with the focus person.

Chapter 4

- Assisting people to define and pursue a desirable future tests one's clarity, commitment, and courage. Person-centered planning engages powerful emotional and ethical issues and calls for sustained search for effective ways to deal with difficult barriers and conflicting demands. Those who treat person-centered planning simply as a technique and those who fail to provide for their own development and support will offer little benefit to the people they plan with.

HOW DOES PERSON-CENTERED PLANNING INFLUENCE CHANGE?

Person centered planning influences change by …

… creating a compelling image of a desirable future and inviting people to join with the focus person to make it happen

… strengthening personal relationships

… helping people plan, act, and learn by reflecting on their successes and failures

When successful, person-centered planning allows its participants to experience tension between what is desirable for a person and what exists now for the person. This tension can energize action for positive change.

What is desirable for the person

What is now for the person
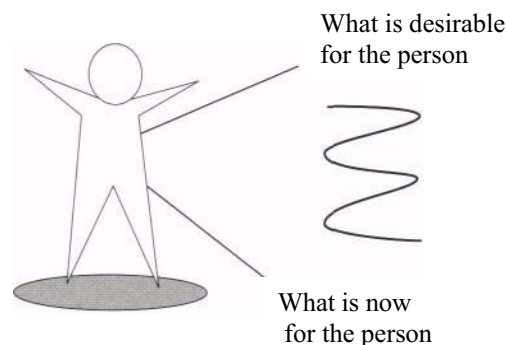
Too often, however, the inertia of service systems couples with prejudice against people with disabilities to stifle hope and opportunity. For

change to happen, community opportunities must be opened and expanded and service systems must develop new capacities, both within themselves and in the wider communities they must be a part of.
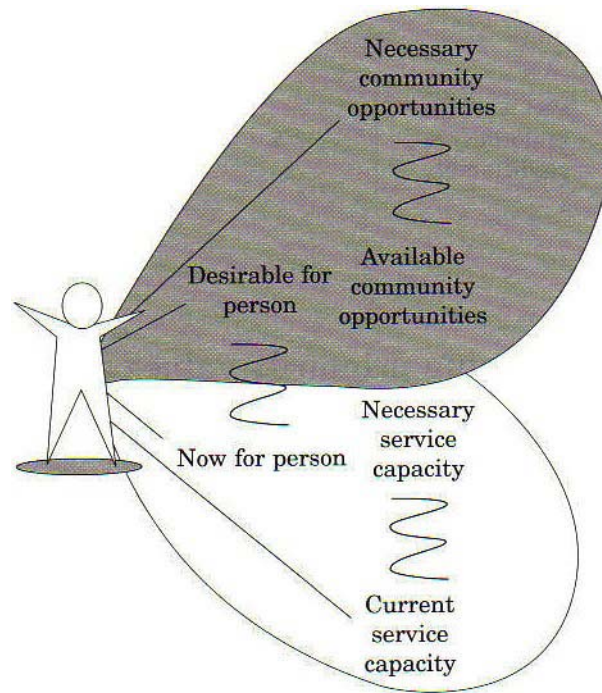
This development happens through a process of mutual adaptation: first, services change to create new supports for the person and then the person responds to the demands and the rewards of the new situation. This sequence contradicts the tradition that people with disabilities must change themselves as a condition of entry to new opportunities: environments effect change more powerfully than training can.

Person-centered planning influences change when people respond to the tension between what a community has to offer now and what the focus person needs to pursue a desirable future. Direct engagement with the focus person and the focus person's allies guides community development. Person-centered planning is a source of clear invitations to community members.

Person-centered planning frequently challenges the culture of most human service agencies. Despite many capable staff who care about what happens to the people they serve, service system culture typically values uniformity and predictability more than the needs of any single individual.

good = greater uniformity & predictability

VS

good = greater variety & new problems
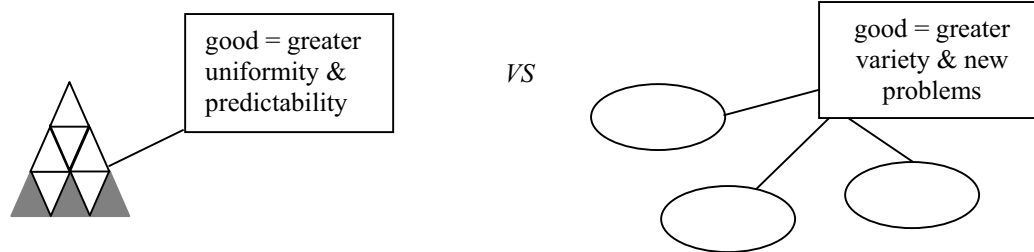
Person-centered planning primarily values accurate individual services. This greatly increases the required variety of service responses.

When uniformity and predictability are primary system values, "individual program planning" functions to decrease uncertainty and variety through a regulated, impersonal ("objective") process of judgment that specific people's daily routines in the pre-existing service option that best matches their disabling condition. The purpose and effect of individual program planning is to make the system more stable by drawing clear boundaries between staff and client and by teaching staff and families and people with disabilities a way to think about people's needs that matches the system's routines.
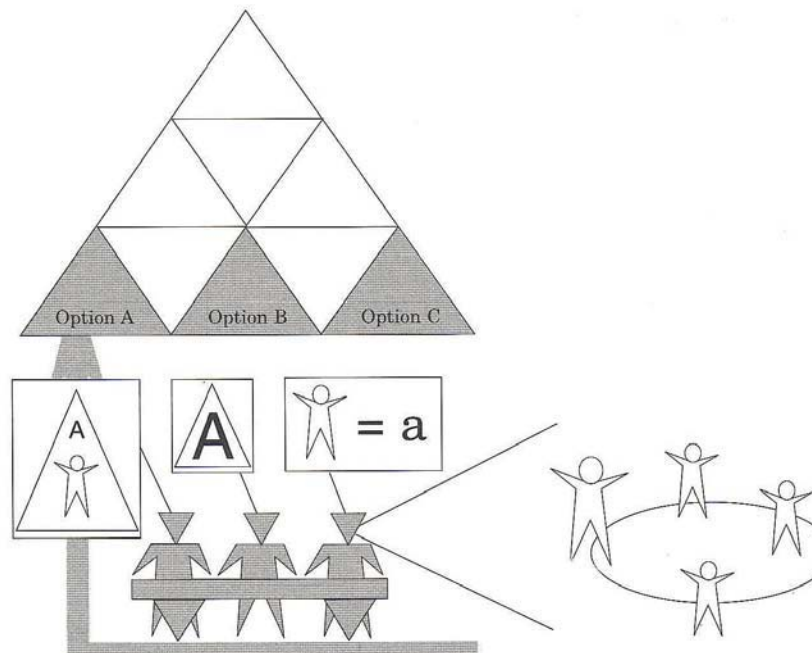
Individual Program Planning: Reduces system uncertainty by complying with rules governing . . .

- Measuring the person
- Assigning the person to an available option
- Prescribing and monitoring treatment
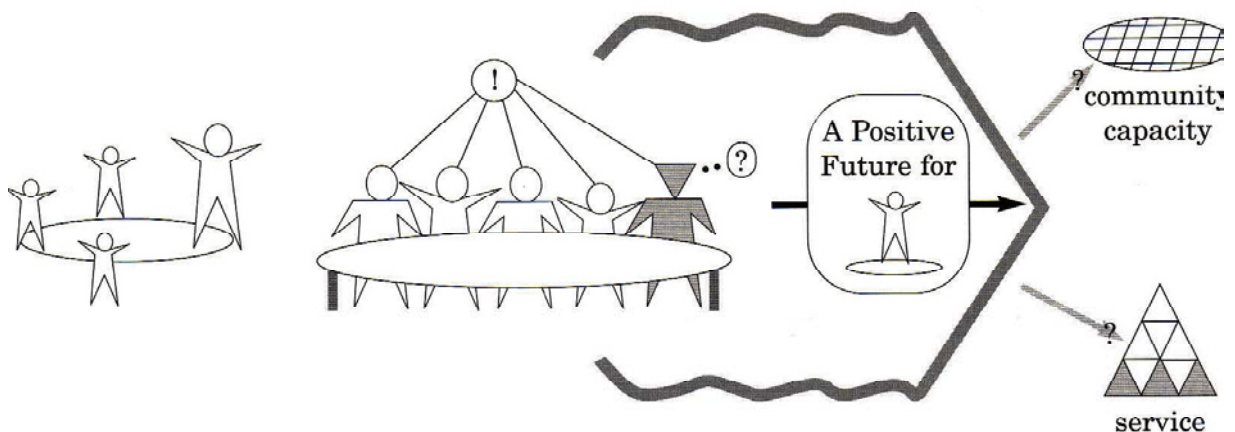
Person-Centered Planning: Increases system uncertainty by . . .

- Strengthening the person's alliances
- Clarifying individual interests and needs
- Energizing new demands on system and community

We have historically been more efficient in providing people for services than services for people. Person-centered planning reverses this tradition to create a personalized image of a desirable future and a problem solving process for moving toward that future. In effect,

effective person-centered planning destabilizes a system for individualized schedules and types of assistance. The questions of how best to understand this person and how best to refine this understanding in action are central to the process instead of being the givens of regulations and professional training. Boundaries between professional and client are dissolved in the search for equal, non-coercive relationships. Boundaries between service agency and community are redrawn as people seek to develop new opportunities. While some people will find these yet-to-be-charted areas of work exciting, others, understandably, will find this unsettling and threatening.

Those who want to can find many ways to avoid engaging the tension between current reality and a desirable personal future. They can compare the present to worse past conditions instead of comparing it to desirable future capacities. They can dismiss the image of a desirable future as unrealistic. They can say that they would like to help but that powerful outside forces forbid them. They can stay busy with activities that allow no time to listen to and learn from focus people.

Individual, community, and service development all happen through a learning process which builds on existing capacities and searches for ways to deal constructively with obstacles. Capacities and obstacles come from local relationships among people with disabilities, families, community members, and service agencies as much or more than they are imposed by uncontrollable outside forces. Person-centered planning provides a systematic way to learn from sustained action over the months and years necessary for development. If the process is successful, people's sense of a desirable future will evolve. One of the most common misunderstandings of person-centered planning is that it is a short series of meetings whose purpose is to produce a static plan. This misunderstanding leads people to underestimate the time, effort, uncertainty, anxiety and surprise necessary to accurately support people's lives over time.

LIMITATIONS OF PERSON-CENTERED PLANNING

Done competently, person-centered planning focuses and directs the energy available to the focus person. Each effort uniquely contends with limits on effective action by the focus person and the focus person's allies.

Sometimes limitations come from the service system. Many administrators like to talk about paradigm shifts without investing in the hard work required to make basic change in the way an agency operates. At times one agency or part of an agency will want to make more change than the system that contains it wants to accommodate. Substantive change cannot happen when service workers are unclear in their commitment to change, and administrators offer lukewarm support. Some service systems are so incoherent or inert that person-centered planning contributes to good results only for people with very energetic and creative family and friends.

Sometimes limitations come from the focus person.

- The focus person provides some of the energy necessary for change.

  - Some people's interests and gifts are clear to others and so their ideas about a desirable future offer others definite ways to be involved; others' interests and gifts are more difficult to discern or support. Experience shows that people's apparent level of ability does not relate to the clarity with which they can communicate their interests or enlist other people they know to assist them. However, person-centered planning will usually move more slowly and have a narrower reach when a focus person's interests are not clear. It has also been our invariable experience that people's interests are unclear until they have people in their lives who combine their love with optimism.

- Some focus people welcome other people into their lives; others challenge those who would establish a relationship, sometimes because they have been repeatedly abandoned or abused. Many people with a reputation for being very challenging respond well to the attitudes implicit in person-centered planning, but person-centered planning often requires hard work to establish, and maintain, relationships when the focus person has a difficult or painful history of relating to others. Person-centered planning is not a remedy for people who are difficult to serve, but it can guide dysfunctional services to provide better contexts for people's growth.

- The focus person's family can make an important contribution, and person-centered planning often provides an effective vehicle for families to have the kind of influence they wish.

  - Family members often have connections to community life and can invite their friends to become involved.

  - Family members often hold the stories that define the focus person as a person rather than a "client." Where services often lose a person's history, or narrowly understand it in terms of professional assessments, families can hold the person's individuality in the foreground of discussions.

But family members can lose touch with a focus person, sometimes because of service practices that discourage family involvement.

- Family members and professionals alike can define people in clinical terms.

  - Both family members and professionals can have more influence over than involvement in a person's life. Sometimes professionals have advised family members not to get "over-involved." Similarly, professionals with the most power in people's lives often do not have much direct contact with them. Psychologists may write

influential assessments on the basis of very brief encounters, and administrators can make life-defining decisions based on service expediency rather than a compelling sense of the person's identity and needs.

- This atmosphere of remote control casts people in a negative light. This focuses planning on people's perceived deficits rather than their capacities; on what could go wrong rather than on what people need for things to go right. When power holders— whether professionals or family members—persist in seeing people in discouraging ways, desirable personal futures become difficult to achieve indeed.

Some limitations on person-centered planning come from the amount of learning necessary to create the opportunities and supports a person needs. Even with strong leadership from the focus person and family and commitment to change by service providers, some issues— such as helping people to make friends, or discovering positive daytime roles for people with high needs for assistance, or finding a constructive way to deal with offenses against the law—are complex and require commitment to the person, often over years.

Person-centered planning is not a "quick fix" for people's difficulties. When things do work well, the lessons don't necessarily generalize widely. What seems to be one person's dream could easily be another's nightmare. In this sense, person-centered planning accurately reflects ordinary life.

Some limitations come from the time it takes for things to happen. One focus person's dream, for example, was to live in a housing cooperative, but organizing the cooperative took several years.

These limitations make responsible facilitators of person-centered planning careful not to promise good outcomes from every effort or speedy delivery of personal or organizational change. Responsible policy

makers and administrators act cautiously and deliberately when they adopt person-centered planning as a means to attain agency objectives on bureaucratic timeliness.

CONTROVERSIES AMONG PEOPLE ENGAGED IN PERSON-CENTERED PLANNING

Like any effort that attracts people with a strong desire to contribute to positive social change, person-centered planning has its share of controversies. These debates cut across the different approaches and identify critical areas for the development of person-centered planning.

- Involved people differ about the extent to which the focus person should control the direction of the process. Some people, emphasizing the history of services dominating people's lives "for their own good," want the process only to respond to what the focus person clearly communicates that he or she wants. They say that the process should be "person-driven planning," with the focus person unequivocally in the driver's seat. Others, emphasizing the history of services depriving people of opportunities for experiences and relationships, believe that other people must actively invite the focus person into new experiences and new relationships.

- Some people who facilitate person-centered planning would refuse to assist a person who clearly chooses to seek to live in a congregate, disability segregated setting. Others believe that alliance with the person is primary and believe that the process should serve whatever choice of living and daytime arrangements focus people or their families make.

- People who facilitate person-centered planning differ in the amount and kind of information they use. Some choose to enlist the focus person and others in making a broad profile of the person's history, present experiences, and ideas about desirable futures. Others focus

on a particular facet of a person's life, such as the necessary and desirable specifications for a person's next living arrangements.

Some people who facilitate person-centered planning are deeply concerned about working within organized service settings. They believe that service systems will inevitably pervert the possibilities of person-centered planning and choose to work at the very edge of the service system, encouraging people to get out of, or avoid moving into, the system. Others believe that person-centered planning can contribute to reforming services by stimulating, or even requiring, different kinds of service practices. They encourage adaptation of person-centered approaches to fit service system agendas like de-institutionalization or development of new programs.

Some people who facilitate person-centered planning believe that person-centered planning should focus on those people who now get the least service from the system: those living with family members. They see person-centered planning as a powerful support to families with disabled members at home and believe that focusing person-centered planning on people already in some kind of residential service is another case of ignoring the many people who have only a little share of system resources in favor of the relatively few in high cost, high visibility services. Others believe that person-centered planning is a particularly effective way to develop better alternatives for people in costly but restrictive and segregating settings.

People who facilitate person-centered planning disagree about how much a person's family, friends, neighbors, and co-workers or fellow students can do and should be expected to do. Some believe that natural supports (i.e., unpaid people) should and can be sufficient to assist people and that their contribution is blocked by the presence of human service workers. Others believe that, while natural supports make a vital and irreplaceable contribution, paid help is

necessary and desirable. Still others are uncertain about whether unpaid people will respond on a sustained basis.

- People who facilitate person-centered planning differ about the importance of convening an identified, ongoing support group for the focus person. Some see person-centered planning as a means to the formation of a circle of support and believe that the circle matters much more than the planning process. Others believe that requiring a defined circle of support is somewhat contrived and could deprive some people who are isolated of the benefits that can come from a good plan. Some debate whether paid service providers can be full, effective members of support circles.

A COMMON FEAR: THE DEBASEMENT OF PERSON-CENTERED PLANNING

Regardless of these controversies, most people who facilitate person-centered planning worry that a system more interested in fads than in fundamental change will capture person-centered planning.
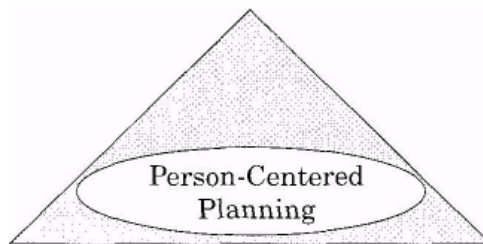
Rather than take on the hard work of learning new ways to assist people, service providers can more easily adopt the vocabulary and some of the techniques of person-centered planning. Often this process is not conscious: service providers simply assume that their current beliefs and practices exhaust all of the positive possibilities for the people they serve. It is not so much that they hear people's call for basic change and reject it, as that they listen to people in a way that confirms the Tightness of what the system is doing now.

Some signs that person-centered planning has become a system fad rather than a tool for change include:

- System boundaries remain intact. Most of the participants in person-centered planning are system workers. There are few efforts to engage community members. There is little reallocation of agency resources into community settings.

- Large numbers of people "get" person-centered plans, but there is little work on creating new kinds of relationships, new service approaches, and new community opportunities. Often this is justified as fairness because administrators believe it would be inequitable to provide something new for a few of the people they serve. This assumes that the system actually has the capacity to respond to everyone's needs. Otherwise, everyone gets a brightly colored bit of paper that describes a future that no one can assist them to pursue.

- The system gives people plans and meetings instead of necessary cash or needed and paid-for assistance.

- Most talk about person-centered planning focuses on how to improve facilitation of planning meetings rather than on how to change the agency's culture and strategy for investing in community opportunities.

- Administrators require person-centered planning without committing any flexible resources and without a procedure for changing regulations and timelines that create real barriers to necessary changes.

Chapter 4
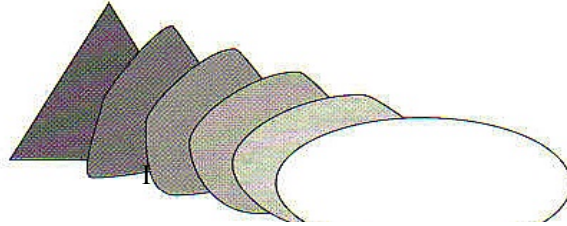
- Administrators, rather than the people involved, tinker with the procedures for person-centered planning in order to make it more efficient and more uniform. For example, administrators decide that person-centered plans take too long and must therefore be completed in a fixed amount of time.

- There is limited investment of time for reflection on what people are learning from person-centered planning.

- Person-centered planning is expected to produce "good stories" more than criticisms and questions about the culture and policies of the service system.

Person-centered planning can also be defeated by its enthusiasts. Practitioners can paralyze themselves by agonizing over the problems and ambiguities surfaced in the process instead of looking for small positive steps. Practitioners can disempower themselves by looking for high ground from which to observe and criticize rather than looking for common grounds for action.

Some Possible Safeguards for Person-Centered Planning Which Can Be Initiated by the People Involved

- Start small and grow slowly, perhaps with projects that are specifically resourced as development activities.

- Join and invest in building up a network of facilitators and other involved people who can offer mutual support and criticism. The network will grow as people ask for and give one another help.

- Identify and discuss conflicts, uncertainties, and poor outcomes.

- Take advantage of opportunities to learn such as reading and training related to human service values and group leadership.

- Seek advisors and mentors.

Chapter 4

SOME DISTINCTIONS BETWEEN APPROACHES TO PERSON-CENTERED PLANNING

From a common foundation of beliefs, each approach to person-centered planning builds a distinctive structure to assist people with disabilities and their allies to clarify direction and plan action.

Individual Service Design

Individual service design developed as part of a long-term effort to assist service providers to understand the practical implications of the principle of normalization (social role valorization). It is often used to help service providers develop positive approaches to people who challenge their ability. The process builds understanding of, and identification with, the focus person by carefully reconstructing the focus person's history. The individual service design group attempts to "walk in the person's shoes," emphatically asking what it would be like to experience the events in the person's life. On the basis of key themes

3. What would have to happen to meet those need? (Be exact)

2. What does the person need?

1. Who is the person:
- A biography
- What would it be like to have experienced what they have?
- Where might challenging or unusual behavior have come from?
- Summarized themes
- ✓ Use plain English!
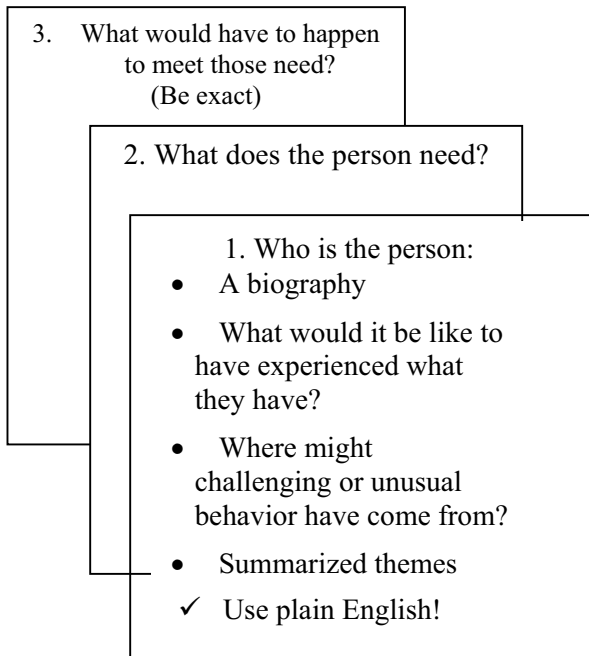
derived from reconstructing the focus person's history, the group identifies the person's most important needs and specifies what would be necessary to meet these needs.

Individualized Service Design

Personal Futures Planning

Personal futures planning developed from efforts to apply some lessons from the fields of planning and community development to the situation of people with disabilities. Personal futures planning has evolved in two different contexts: support to people with disabilities and their families and friends who begin work with little effective cooperation from the service system; and, assistance to service providers who want to transform the system they work within. The process engages its participants in . . .

. . . seeking capacities in the focus person, among those who care about the focus person, and in the focus person's community

. . . discovering a vision of a desirable future with the focus person and making an action plan

. . . building stronger and more effective support for the person by joining people in a process of learning through making small positive changes

specifying and working for changes in the service system which would allow the system to offer more relevant assistance
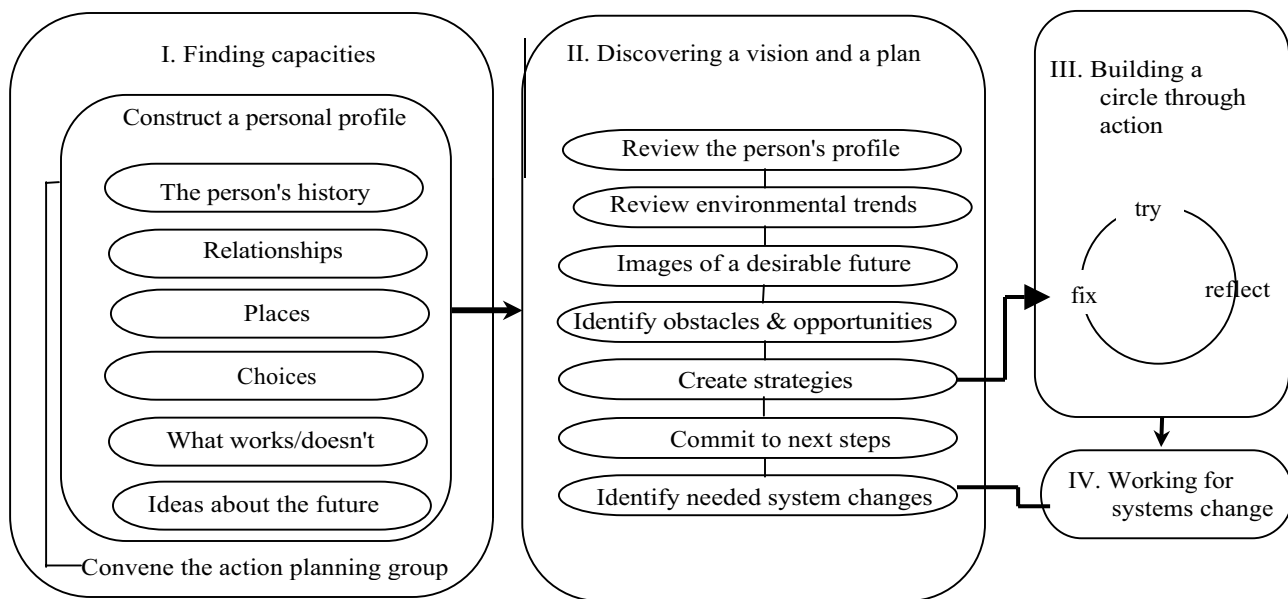
Personal Futures Planning

Personal futures planning calls on all of its participants to work creatively together over time as equals across usual organizational and status boundaries.

MAPS

MAPS developed from efforts to assist families to include their children with disabilities in ordinary school classrooms. The process brings together students, school staff, and family members to create a shared understanding of the focus person and to clearly identify the focus person's gifts and needs. Based on this shared understanding, participants negotiate modifications to school, family, and individual routines. The *MAPS* process is closely linked to the creation and development of circles of support for the focus person and often for the family and sometimes for the staff involved. Circles carry on the day-today problem solving necessary to make and sustain change.

Chapter 4

```
       What is          What is the
       a MAP?           person's
                        history?

                                    What is the
                                    dream?
   The plan of
   action              MAPS
                                    What is the
                                    nightmare?
   What does the
   person need
   now?            What are the
                   person's gifts,   Who is the
                   strengths, and    person?
                   talents?
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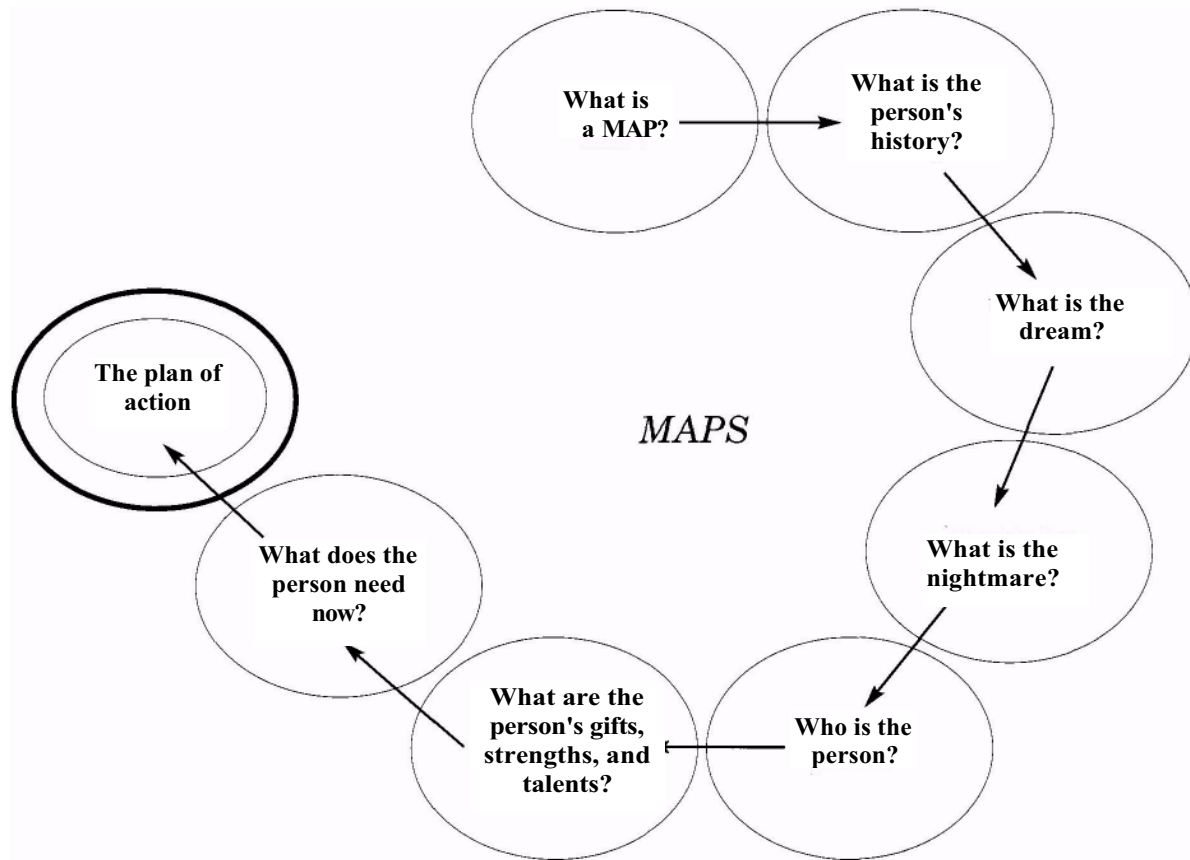
Essential Lifestyle Planning

Essential Lifestyle Planning developed from efforts to assist people to move from institutions into community services. The process focuses on gathering information about the focus person's core values and preferences from the focus person and from those family members, friends, and institution staff who know the focus person well. This information becomes the basis for a request for proposals from service providers and is finally incorporated into a contract between the service system and the service provider who chooses to assist the person. An independent agent typically directs this process. Essential Lifestyle Planning aims to provide the focus person with a secure and effective base of service assistance.
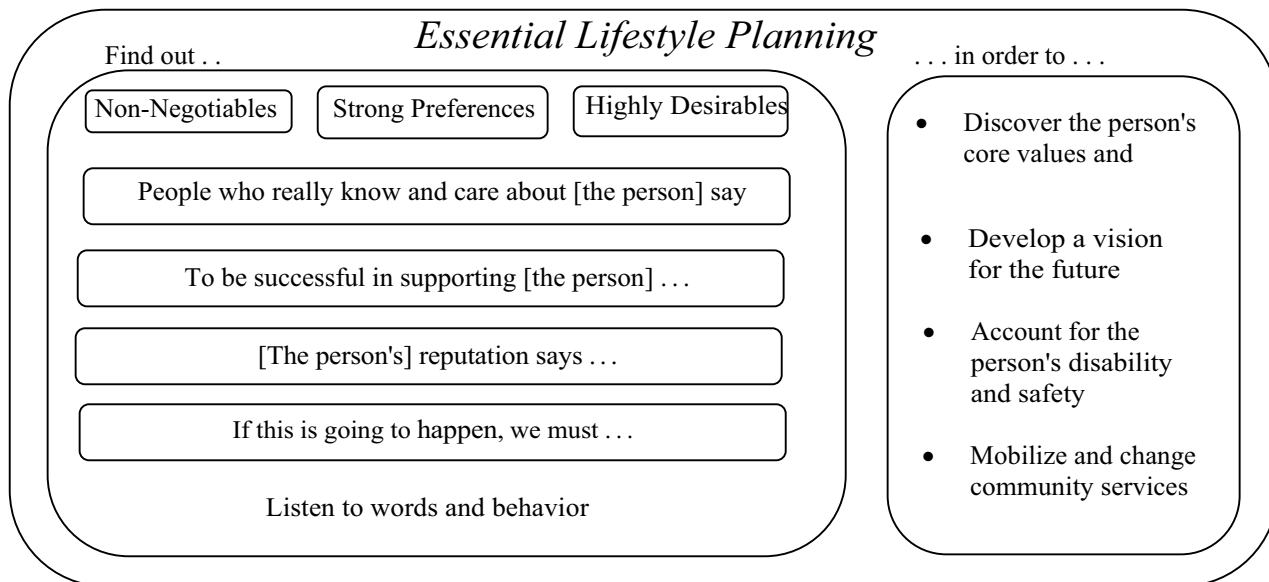
Essential Lifestyle Planning

Find out . .

| Non-Negotiables | Strong Preferences | Highly Desirables |

People who really know and care about [the person] say

To be successful in supporting [the person] . . .

[The person's] reputation says . . .

If this is going to happen, we must . . .

Listen to words and behavior

. . . in order to . . .

- Discover the person's core values and

- Develop a vision for the future

- Account for the person's disability and safety

- Mobilize and change community services

THE FUTURE OF PERSON-CENTERED PLANNING

Person-centered planning can invite, align, and direct shared efforts to create positive community roles for people with disabilities. It allows people to exercise their practical wisdom to work for more inclusive, more just communities.

To support their work and its improvement, people involved in person-centered planning need to extend their network of relationships across the different approaches to person-centered planning, community development, and service reform. The future of person-centered planning depends on their willingness and ability to improve their practice through critical reflection on the effects of their work in the lives of people with disabilities and their families.

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*Note: Some people call this approach "lifestyle planning," probably because copies of O'Brien's chapter by that name (1987) were widely circulated. This chapter was written about personal futures planning, which was renamed lifestyle planning by the book's editors in the context of its application to the activities catalog approach to school curriculum development.

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Jack Pealer and Sandra Landis (1990). *Suggestions for exploring and recording the personal history of someone we're assisting to plan.* Chillicothe, Ohio: Ohio Safeguards.

Contact: Communitas • Box 374 • Manchester, CT 06040
Graphic Futures • 25 West 81st St, 16-B • New York, NY 10024
Minneapolis Governor's Planning Council on Developmental Disabilities • Centennial Office Building • St Paul, MN 55155
Ohio Safeguards • PO Box 1943 • Chillicothe, OH 45601
Realizations • PO Box 1430, Station B • London, ON N6A 5M2 Responsive Systems Associates • 58 Willowick Dr • Lithonia, GA 30038

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Individual Service Design

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Contact: Jack Yates • Ralph Mann Dr • Stoughton, MA 02072

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Contact: NASMRPD • 113 Oronoco St • Alexandria, VA 22314

MAPS

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Contact: Inclusion Press • 24 Thome Cres. • Toronto, ON M6H 2S5

ESSENTIAL LIFESTYLE PLANNING

Used with Permission of and Special Thanks to:
Michael Smull, Baltimore, Maryland

The headings

In "essential lifestyle planning," as in the other forms of person-centered planning, we conduct the meeting using "wall paper." A series of charts are placed on the wall with headings that help organize the information needed to implement community services for the individual. The headings for the charts are:

- Non-negotiables

- Strong preferences

- Highly desirables

    People who really know and care about _____ say—

    To be successful in supporting_____

    _____'s reputation says—

    If this is going to happen we must—

The first three categories—non-negotiables, strong preferences, and highly desirables—ranks what people like and dislike. Keep in mind that while these distinctions can be very helpful they are artificial; good sense should prevail. The next set of headings serves a number of purposes. What people who really know and care say about you is your positive reputation. This begins to counter the reputation found in the record. The heading that says "to be successful in supporting _____" is where the issues of those people who are essential to success and the essential clinical issues are noted. The reputation heading serves two purposes. It gives those who are compelled to recite the past a place to do it, but it also insures that attention will be paid to issues that can be glossed over in the positive focus of the meeting. The last heading on the chart is where action steps are described. The "who, what, and when" are described in order to sustain the momentum of the planning process.

Non-negotiables

Non-negotiables are those lifestyle choices which are essential to a reasonable quality of life for the individual. Positive non-negotiables are essential for a person's life to be tolerable and pleasant. Negative non-negotiables make life so unpleasant and intolerable that their presence will make people act out or withdraw. Non-negotiables represent the core values and characteristics of individuals. Examples of non-negotiables in plans that have been done are:

- not living with smokers

- having lots of friends

- living where I grew up

- living with people who do not mind clutter

- living with people who "love me the best"

- not living in the city

- control over my own space, my own possessions

All of these requests are modest. The non-negotiables we find for people with disabilities are rarely honored and yet readily available to typical citizens in our communities. We refer to these preferences as non-negotiables because they are essential to the individual's well-being. They are the choices that we must honor. Providers who cannot (or will not) meet these are not considered.

Most non-negotiables are stable over time but some of them do change. Where change occurs it typically reflects learning. We find that core values and the choices they reflect evolve over time. As we mature we find that what we value shifts. Often we want more stability and less change. We also make choices that do not have the anticipated results, that do not give us the increase in our quality of life we expected. The

cliche for this is "learning from experience." When ordinary people make a particularly bad choice we call it "learning from the school of hard knocks." In the disability field, when we are angry with someone and "let them fail," we call it "suffering the natural consequences."

Strong preferences

Strong preferences are the middle ground between non-negotiables and highly-desirables. For example, there are people who simply cannot stand to be around cigarette smoke, those who have a strong dislike, and those who simply find it irritating—people with a non-negotiable, a strong preference, or a highly desirable. Strong preferences reflect those choices that make a major contribution to a reasonable quality of life but are not critical to it.

Highly desirables

Choices that are the highly desirables represent those things we would like to have. We are not interested in a Christmas list of things that someone might like. We are seeking to discover those things that people know that they want in their lives. Most of us have lists with a pyramid shape—we have a few non-negotiables, more strong preferences, and lots of highly desirables. Where there is a short list of highly desirables we either do not know the individual very well or the individual is living a very impoverished life. Just as in the other areas, most highly desirables are typically quite modest. We should be able to support people in having many of their highly desirables met.

In thinking about choices and planning

Where services that honor these choices do not exist, we need to plan further. Can we find the setting and then build supports around the individual? How long will it take to develop the setting that meets the

non-negotiables? If the answer is months then we need to see if there are interim efforts that will improve life while the individual waits. We must guard against having interim become permanent. Too often the interim efforts remove the pressure needed to develop the setting that meets the non-negotiables. We must ensure that the non-negotiables will be met.

Where we are planning for others we need to take into account that our understanding is always less than perfect. We are often trying to support people whose disability and circumstances preclude a clear vision of a desired future. Difficulties in speaking for themselves, impoverished life experiences and few connections with people who know and care about them increases our challenge. We need to see all of our lists as representing the understanding that we have at that moment. As our understanding changes we need to change our lists.

Quality of life is interactive and evolves over time. There are synergistic effects. The presence or absence of a reasonable quality of life is made up of a complex of interacting issues. The product of the interaction cannot be easily predicted. We need to pay attention to how people feel about their entire life. We need to continue to learn not only about the effects of single choices but the effects of their interactions. In looking at individuals' perceived quality of life we need to account for their personalities. Edgerton has noted that pessimists and optimists tend to stay that way. Assessments of how people report on their quality of life need to reflect the "baseline" of their personality style.

People who really know and care
about her/him say

How would your mother describe you when bragging to her friends? The stereotype of a mother's description is how this section should be approached. All of the positive attributes of the individual that relate to

human interactions or valued skills would be listed here. Adjectives such as "charming" or "warm"; descriptors such as "loves to help others" or "makes me laugh"; skills such as being an "excellent baker" or plays a "great game of pool"; are all appropriate examples. Clinical descriptors such as "has all his ADLs" or "expresses anger appropriately" are not acceptable.

Few positive descriptors means that you have not invited (or interviewed) the right people or the person needs to move immediately. People who know and care about someone always have reasons why they care. Their stories carry the positive descriptors. If you have sought out these people and have not found them then the individual is living without people who care. Anyone living without people who care needs to leave as quickly as is possible.

To be successful in supporting her/him

If we are to be successful in supporting people with severe reputations we must do more than honor their choices. We need to address their clinical needs. We need to address all of the prerequisites for the individuals to achieve their desired lifestyle in the community. We cannot assume that behavioral issues will simply cease to exist because people are getting the lifestyle that they are asking for. For an individual who throws and breaks things when he gets angry we cannot assume that he will no longer get angry. There need to be reasonable, positive practice behavioral plans to deal with predictable challenging behaviors. Other clinical support issues may be medical, psychiatric, or neurological. Any essential clinical supports needed should be listed.

This is also the area where the issues of other essential people are addressed. In one instance it was critical that an individual's mother be enlisted as an ally before the individual moved. This is an individual who has a close relationship with his mother and she has correctly perceived that we have not done well in supporting her son in the community. For

another individual, whose living arrangements crossed funding jurisdictions, officials from both county services boards had to agree before the individual could move.

His/her reputation says that he/she

Reputation needs to be approached with caution and judgment. When you are planning with people whose reputations are the primary barrier to achieving their desired lifestyle, the reputation must be confronted. But you must also keep in mind how difficult this can be for the individuals who are experiencing this public-parade of past sins. Consider whether this section is needed. It can serve a number of purposes.

First it provides the facilitator a place to consign all of the negative attributes that some people have a compulsion to emphasize. Second, it can be used as a contrast with the positive attributes of the individual and demonstrates how we blame individuals for system problems. Finally, in the process of describing the reputation, we can be alerted to issues that we must account for. Occasionally people feel that the positive emphasis of this planning process precludes raising issues of real concern. For example, someone who has set fires presents a public safety issue that we be adequately prepared for.

The reputation listed in the preliminary plan needs to be shared with the individual and a strategy developed to assist the individual in coping with it. The terms used should be carefully considered to see if they impart the necessary information while they are as respectful of the individual as is possible. Alternatives can be considered as well. Where the planning is being done with people without severe reputations, you need to consider whether this section is needed at all.

If this is to happen we must—

As the planning meeting ends, the momentum that has been created must be sustained. A set of concrete action steps should be developed. They are listed under this heading with the action, the date by which it is to be accomplished, and who is to accomplish it. A list which includes everything up to the move of the individual is unusual. It is more important to establish realistic time frames for moving forward with the plan and to make the planning participants responsible for its execution. The last step is typically a date to get back together to report on progress and continue the planning.

PREPARING FOR THE MEETING
Disputing the reputation—
understanding the person

Understanding the person is not a "Pollyanna" process where the difficulties are glossed over by denouncing the service system. Understanding the person suggests that all people are complicated and require more than simple assessments of splinter skills or isolated behaviors. Understanding the person also suggests that people with severe reputations have positive attributes. They have gifts, skills, and potential contributions. Understanding the person requires that we look beyond the reputation to the whole person.

First, we must get to know the whole person. We must move from traditional, deficit-oriented assessments to understanding the person as a real person. We must go beyond simply identifying strengths and needs and discover what the core values are for each person. It is not enough to focus on preferences, we must know each person's dreams and night-mares. We must remember that we can easily make someone's nightmares reality.

It is critical that we know what the values and hassles are for each person. There are few relationships, jobs or situations that are totally hassle-free. We choose to continue in these situations when the values outweigh the hassles. We choose to leave when the hassles outweigh the values. We must recognize that a major difference between ourselves and people with disabilities is that they do not get to "walk" when the hassles outweigh the values. They only get to leave when we allow them to leave.

Meeting the person—not the reputation

We must meet the person rather than the reputation. Find a setting where the individual is comfortable, where the behavioral norms of the setting are not elicited. It can be private space where the individual lives but it might be a hillside where you can sit with a picnic. It might be a restaurant in the neighborhood. It may require that you go along with the person on an outing. We need to keep in mind that the norms of congregate settings are powerful and seek alternatives where the individual is relaxed and comfortable. We also need to keep in mind that many people are shy and will not let you get to know them until they get to know you.

Getting to "know" someone is a social skill more than it is a professional skill. Typical professional skills will elicit social histories or determine mental status but will not help you find out who the whole person is. You need to talk about the good times in the individual's life. When did things go well from the individual's point of view? What are their favorite activities? Who do they feel close to? Who would they like to have involved in their lives? What do they like, what do they really enjoy? What annoys them, what makes them angry?

How much people can share verbally depends on their abilities as well as the relationship you establish. Regardless of the verbal skills there is

much that can be shared and learned. We need to take the time to get to know them as individuals and not rely solely on informants. However, because many people with disabilities are poor historians and because we have given them extensive training in telling us what we want to hear, we also need to interview others.

Selecting "informants"—recruiting allies

We typically find no shortage of professionals who can tell us what is wrong with an individual. To understand the person we need to be able to talk to people who know the person rather than their disabilities. We need to talk to the people who know what is right with the individual, who can tell us why they like the individual.

Find the people who enjoy spending time with the individual. There are no rules about who these allies can or cannot be. For individuals who live in institutions they may be from housekeeping or from the professional/management staff. The only rules for selection are that these people must like the individual and enjoy spending time with him (or her). Look for people who spend extra time with the individual. If there is no one at this moment, start going back in time. Where someone has lived in a facility for years there are almost always people who really know and care about the individual.

Look for family or friends who are available and interested in the individual. They are typically the best historians for the individual's likes and dislikes over time as well as for information about the times when things went well. Unless they appear to be a destructive force in the life of the individual, encourage their involvement in the planning for the person as well as the eventual supports. The key word is encourage. Do not coerce, use guilt, or otherwise manipulate family into promising involvement that they will not be able to sustain.

Ask:

- What do people generally like about the individual?

- What are the individual's gifts; what does he/she do well, what does he/she enjoy doing?

- What makes the individual unique; how is he/she different from other people; if we were to characterize the individual in two or three words what would they be?

- What does the individual find to be a hassle; what doesn't he/she like doing; what makes him/her angry; what does he/she find to be annoying?

- What motivates the individual; what is important to him (e.g., money, praise, personal appearance, family, church, friends)?

- When have things gone fairly well for the individual? Describe the circumstances, speculate on why things went well.

- Who is important to the individual and what is their relationship (e.g., mother, son, sister, friend, special member of the staff)?

The responses can be as short or as long as the informants would like to make them. These are areas to cover as much as they are questions to ask. Just a[15] much of this planning process is adapted from personal futures planning, interviewers should adapt these questions to their own style and circumstances.

**Using professional information—
looking beneath the labels**

We need to look beneath the labels that the individual has acquired to determine if they contain any helpful information. Some labels tell us very little that is useful while others provide critical information. No

label tells us where people live or what work they should do. Where they are accurate, they can tell us where someone should not live or what situations we should avoid.

As many labels are not accurate, we need to start with skepticism. Some people with severe reputations seem to have acquired labels as if they were party favors. They got the labels by simply being at a facility where someone was passing them out. They did not get the label by meeting a set of criteria. They may have exhibited behaviors that were misinterpreted, not examined, or elicited by an atypical institutional environment. Some labels reflect behavior that was present in the past but which is no longer an issue.

People with severe reputations typically have psychiatric or behavioral labels. Some labels give us critical information. If we ignore or dismiss these labels, we can cause the very failures that we are seeking to avoid. Someone with a bipolar (manic-depressive) disorder must have careful, competent psychiatric care. Someone with a history of severe depressions or psychosis will need careful monitoring so that prompt appropriate treatment is given for recurrences.

We need to be particularly careful with the labels that are "loaded." People with labels of pedophilia or arson are rarely welcomed. Where they do reflect a real condition, we need to take the precautions necessary to assure the safety of the community. Yet, these labels rarely reflect a compulsion on the part of the individual. Typically they were not correctly applied and have no current relevance. A number of people have labels relating to aggression, such as intermittent explosive disorder, whose real histories describe someone who is rarely listened to. Labels that are misapplied, or are no longer relevant, are simply another barrier to life in the community.

Mining the records

While the typical record of an individual with a severe reputation is replete with accusations it can also be the source of significant information. Careful review can yield information about how to help the individual and who else to involve in helping. By reviewing the stories of repeated failures we can prevent errors in our responses to the individual. Reading the record from a "person-centered" orientation will tell us much of what the individual does not like or will not tolerate. There are often clues as to the characteristics of people that the individual does like and what the individual finds to be valued. Current and past social histories should be carefully reviewed for clues regarding family or significant others who may be available to provide supports in the future.

Developing preliminary lists

As you are collecting information about the individual you should be organizing it. Is this a non-negotiable? Is it part of the reputation? Once all of the pre-meeting information has been collected it should be put on charts. Make charts with the various headings and begin to put the information on them. The most difficult part is deciding what is and is not a non-negotiable. Keep in mind that part of the purpose of the meeting is to review, revise, expand the information on the charts. Keep notes of your questions and uncertainties. Sharing your questions about what should go where is an excellent way to initiate and sustain discussion.

Information on the charts should be free of jargon and in everyday English. The only exception is listing clinical labels on the "reputations" chart. Do not worry about having complete information at this point. The purposes of developing preliminary charts are:

- To organize your thoughts;

- To discover what you know, what you do not know, and what you are not sure of; and

- To provide a place for people to start, to give them something to react to.

Inviting the right people—determining who is needed, who is essential

The people who need to be invited are those who know the person the best and those who are essential in the implementation of the plan. People who really know the person can help sort out what is a non-negotiable and what is a highly desirable. You need not invite all who must approve the plan but you need the people who will be responsible for its implementation. They will be educated by the process. Many of them will meet the person (rather than the reputation) for the first time. If you can move the whole person to the foreground and the reputation to the background, skeptics can be changed to allies through their participation in a good planning meeting.

However, this is another area where common sense and good judgment must prevail. People who have profoundly negative feelings about the individual will adversely affect the meeting process and outcome. Do not invite them. Among those who know the individual there may be some whose schedules just do not allow them to come when all of the other key participants can come. You will then have to determine whether to rely on an interview to convey their information and insights or to delay the meeting.

Finally there are the key people who are really needed but are "burned out" on the individual and/or meetings about the individual. The first step

in convincing them that this process is different is to spend time listening to them. Most typically they will agree if they feel that you appreciate all of their past involvement with the individual. You do not need to convert them into enthusiasts prior to the meeting; you just need them to agree to participate in the meeting.

CONDUCTING THE MEETING

Setting the ground rules

Large, interdisciplinary team meetings are a ^equent and familiar occurrence in human services. People gather to share their "clinical insights," assessments, and findings in an "objective" setting. Typically, these meetings focus on the individual's deficits (which are labeled as "needs"). The "team's" mission is to "fix" the person. All of the efforts are directed toward moving the individual towards "independence" and "community readiness."

There are several key elements that distinguish an Essential Lifestyle Planning meeting from a typical Interdisciplinary Team Meeting. One of the basic differences is the ground rules that are established and adhered to throughout the meeting. These ground rules should be clearly stated at the beginning of each planning meeting. They are:

1. Use plain English.

Avoid clinical jargon. If we want friends and relatives to participate on an equal footing we all have to use everyday English. Jargon can also serve to distance the individual from the rest of us. Using everyday descriptions, instead of clinical terms, helps to keep the individual's issues in the same realm as our own struggles. It is the job of the meeting facilitator to politely rephrase jargon-laden statements into everyday language.

Whatever is written on the lists at the meeting and incorporated into the final plan should be in language no more sophisticated than that of the local newspaper.

2. The planning meeting should be conducted with, as well as for, the individual with a disability.

The individuals who are the focus of the meeting are always invited to the meeting. If they are absent it should be their choice and not for our comfort or convenience. They should be spoken to directly and never talked about as if they were not at the meeting. The respectful inclusion of the individuals with disabilities during the meeting is a key ingredient to the overall success of the meeting. If people are unable to speak for themselves or if it is not clear what they want, a trusted friend or family member may, through the strength of their relationship, be able to speak on their behalf.

3. Promises for further action are made to the group and not to the team.

As responsibility for the action steps are divided among the participants they must understand that they are undertaking a collaborative process. They are making promises to the person with a disability and the other participants, but not the "team." It is not unusual in "team" plans to set completion dates that conform to expectations rather than reality. If these time lines "slide" the individual will see this as simply another empty exercise. Individuals who trusted the process will be disappointed and may regress in reaction. Realistic timetables and deadlines should be set and those with assignments should be held accountable to the planning group. It is usually more important that an action step be completed thoroughly rather than quickly. Be sure to avoid the seductive trap of over-commitment when setting up the time lines for the steps.

While these three simple ground rules appear to be quite easy to implement, they represent a major shift in "planning behavior." It is hard to break habits and easy to revert to "team meeting" behavior, lapsing

into jargon, ignoring the individual, and making unrealistic promises. The result can be a compromised process which produces a pale imitation of a person-centered plan.

Setting the tone

In this meeting we are to listen to the individual with the disability. The facilitator conducts the meeting on the behalf of the individual with the disability. In this sense, it is the person with the disability who directs and propels the meeting. This is an opportunity for the person's essential lifestyle choices to be identified. Dramatic behavioral incidents of the past must be placed within the context of the person's whole life. Do not allow the meeting to degenerate into a series of professional "war stories." The reputation cannot become the focus of this meeting. Redirect excessive discussion of negative behavioral experiences. For a person with a disability, the negative experiences of the past can become a daily reminder of the most humiliating moments of their lives.

It is equally important that these difficult times not be ignored or glossed over. Rather they should be treated as holding important information for planning. What does the behavior tell us? The key is to learn from each experience and not to place too little or too much emphasis on any incident. One sign of a good facilitator is the capacity to reframe negative accusations into positive statements. A man who "isolates himself may "enjoy being alone." A woman who "resisted doing new and more complex tasks" was discovered to "want to do things that she is good at." Another woman, who was seen as a pest by some staff, was found to "want to have someone who loves me the best." Staff-centered institutions, group homes, and services necessarily cast everything from the perspective of the professional. In a person-centered process we can recast these statements. By seeing them from the view point of the individual we discover behaviors that are not remarkably different from our own.

Keeping it moving and on track

Although the format of the person-centered plan is straightforward and easy to follow, the focus and momentum can be compromised or lost during the meeting. It is easy to become bogged down in excessive detail or psychodynamics. The challenge is to balance process and outcome. We need sufficient discussion to allow people to get past the reputation and focus on the individual. There needs to be enough interaction between the participants so that the synergy of a group process can be tapped. At the same time we need to have a reasonable plan at the end of the meeting and we need to insure that we do not revert to focusing on what is wrong with the individual.

Using the lists as a point of reference will help to keep the meeting focused on the individuals and their lifestyle choices while avoiding the lure of tangential journeys. The facilitator needs to tell people how long the meeting will last and the expected outcomes. Periodically note how the group is doing relative to the remaining time. It is a role of the facilitator to "bring the group back to task" if they get off track. If the group has significant unanswered questions these can be noted and the group can move on. Schedule another meeting to deal with them, where necessary. Typically these questions require additional information as well as additional discussion. The information will need to be collected before there is another meeting.

Building and sustaining momentum

During the meeting the momentum for change and implementation is developed as the individual is seen as a whole person. As the modest requests of the individual are identified, they become the foreground and the reputation moves into the background. This can be exciting! A good planning meeting will energize people to support the individual. They will also need help.

The meeting ends with assignments being made to carry the plan forward as the first step in sustaining the momentum. However, without on-going efforts, implementation will cease. Unlike classical physics (where an object stays in motion unless acted on by an outside force), change in human services only occurs where people keep pushing. One of the goals needs to be to build a "personal network" or "circle of support" for the person. People who have others who care about them in their lives will not have to depend on paid staff to have their choices honored. This is hard to do for most people who have been socially isolated, but for some there are friends or family who only need permission. Where you find that opportunity, give permission.

Collecting additional information

At the end of each planning meeting you need to ask yourself if you feel satisfied in your understanding of the individual. It is not uncommon to find that important questions remain unanswered. Sometimes these reflect the absence of someone that we should have invited or questions we did not ask in an interview. More frequently they reflect the process of discovery that goes on during the meeting. Ending a meeting with unanswered questions is not necessarily a sign of a poor meeting or poor preparation. It can be an indication of how misunderstood the individual has been. The questions arise when we begin to look past the reputation to the individual.

Experience can help the facilitator to have fewer unanswered questions. However, what is immediately at issue is getting the information. Where these questions remain, the first action steps are to find the answers. There are no rules for who is to obtain the information except those of common sense. People who know the individual are logical choices. The facilitator can be the one who gets the information but this may be an indication that there are too few people who are committed to making the plan work.

Writing up the plan

Occasionally writing up the plan is simply a matter of transcribing the lists. More typically, additional information or additional reflection results in changes in the plan. This is the last opportunity to use simple declarative English in describing the individual or the supports. This is also an opportunity to make sure that everything is stated as positively as is possible without misstating who the individual is. This is also an opportunity for reflection. Does the plan capture what we know about the individual? Do the non-negotiables make sense? Include the uncertainties in the written plan. The plan should be seen as a guide rather than revealed wisdom. Remember that it will be implemented by people who were not at the meeting as well as those who were there.

Have the plan typed and distributed within a week of the meeting. If one of the action steps is to get information that is to be included in the plan then the preparation and distribution of the plan becomes an action step with a date by which it is to be accomplished. A key element in sustaining momentum is to put the written plan in the hands of all of the people responsible for its implementation. If they do not get it until several weeks after the meeting it will simply be more paper in an in-basket.

THE PLAN IS AT THE BEGINNING NOT THE END

A successful planning meeting can be the beginning of exciting change for the individual. It is when we stop talking and start doing. Putting person-centered plans to work in a program environment is a challenge. It is also an opportunity. System change is easier when done one person at a time. By focusing on the individual's issues you side-step interminable debates over the number of people who should live together and the rules they should abide by. What remains central is meeting the essential lifestyle choices of the individual. Can these choices be met in existing settings? Then the individual should move to that setting. If it requires something new, we need to create it.

It is essential that we not move from trapping people in a program mentality to trapping them in a plan. The plan cannot be frozen in time and never change. Today's plans reflect our present understanding and knowledge. If the plans are accurate, they are a snapshot of what is important now. As the person changes, as our understanding deepens, the plan should change. We need to make certain that we do not tell people that we will plan carefully once and never again. We have to get into the habit of listening to people with disabilities and acting on what they tell us.

YOUR IPP

(Individual Program Plan)

It's Not Just a Piece of Paper!
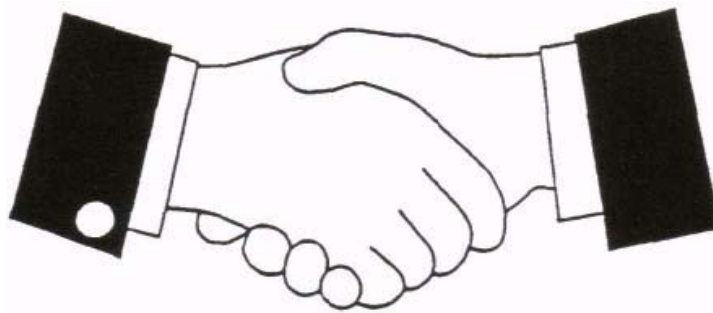
A Self-Advocacy Manual for
People Who Get Services from Regional Centers

Capitol People First and Protection & Advocacy, Inc.
Peer Advocacy Project
1998

THE LAW—THE LANTERMAN ACT

In California, people with developmental disabilities have the right to help and services. The law says that people who get services from regional centers have the right to decide what kind of help they want and need and to make choices about their lives.

The law says that people have the right to make choices about:

Where to live

Where to work

Who to live with

Who to have for friends

What to do for fun

What to do in the years ahead
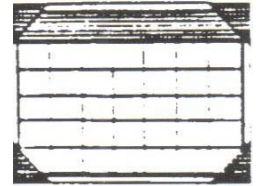
THE LAW SAYS THAT YOU HAVE A RIGHT TO:

Your own written individual program plan (IPP) that lists your goals and the services you need This is also called a person centered plan sometimes, this Manual will use the term individual program plan (IPP) because that is the phrase the law uses.

Services and help that are provided to you in places that are as normal as possible—*not* in institutions or places only for people labeled "retarded," but in natural community places, and
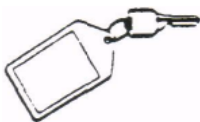
Services that really help you to be a member of your community

The law says that:

Your own written individual program plan (IPP) must list your goals and the services you need to ^ live more independently in the community.

You have the right to be a big part of making your plan.
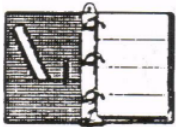
The regional center and other agencies that provide services to you, like group homes and workshops, must help you choose what services you want.

The information you need to choose the services you want must be given to you in a way you understand. This is called "informed choice".

WHAT IS YOUR IPP?

Your IPP is *your* individual program plan. It is *your* own action plan about the *help you need* to live the way you want.
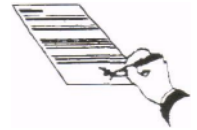
It is a written agreement or contract between *you* and your regional center.

It is made by *you* and your regional center service coordinator (case managers or social workers are now generally called service coordinators) and other people you invite to the meeting. The regional center may also have people it thinks will be helpful to you attend the meeting.
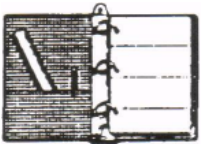
It lists the services that you need and want to be more independent and to live the way you like.

WHY IS YOUR IPP IMPORTANT?

Your IPP is important because it tells about what services and help the regional center will get for you.

Your regional center must provide the services listed in *your* IPP—that is the law (the Lanterman Act).

If something is written in *your* IPP, the regional center must give it to *you.* You are entitled to it. Usually the regional center must buy services for you from another agency.

If something is not written in your IPP, you cannot count on getting it.

Your regional center cannot change what is in your IPP without having a meeting with you. That is in the law too.

WHY IS YOUR IPP *MEETING* IMPORTANT?

Your IPP meeting is important because that is the only time and place where *your* IPP can be officially talked about and written up.

You have a right to be at your IPP meeting and tell people what kind of help and services you need the regional center to get for you.

The regional center cannot write an IPP about you without you being at the meeting.

The regional center must have a person at your IPP meeting who can say yes or no to your requests for services. This may be your service coordinator or it may be a person in addition to your service coordinator. This means that regional centers cannot make decisions outside your IPP meeting about the services you need. The decision must be made in your IPP meeting so that you have a chance to talk with a person who can say yes or no to services you ask for.

If a person who can agree to your request for a service is not at your IPP meeting, the regional center must set up another meeting within 15 days that the right person will be at.

Chapter 4

You and the regional center person must agree on and sign the IPP before the services can be given. If you only agree to part of your IPP, you should ask your service coordinator to prepare a statement that says something like: "I agree to the parts of my IPP of (date) Numbered (--,-,--, etc), but not to the part(s) numbered (—,—). Please start or continue the services I agree to right away." If the regional center says no to any of your requests, the regional center must send you a letter within 5 days telling you why they are not giving you the service you want and telling you how to file for a hearing.

The law doesn't require that you have an IPP meeting more than one time every three years. But, if you <u>want</u> to have one sooner to talk about changes in your life, you can ask your service coordinator to set one up. The meeting must be held within 30 days of your request.

You can ask to have your case manager changed.

You can ask to change programs you are in.

WHAT SHOULD YOU DO TO GET READY
FOR YOUR IPP MEETING?

Be positive. You are good at lots of things and have good ideas about what you want for your life.

Before the meeting, make sure you take time to think about the dreams or goals you have for the future and the help you need to reach your goals.

Before you go to *your* meeting, talk to people you trust about what you want to say at your meeting. Practice being clear about what *you* want.

There is a special IPP meeting planner at the end of this manual to help you plan for your meeting.

Write down what you want to say about *your* dreams and the services *you* want. If you need help writing it down, ask a friend to help you.

If you have trouble writing or get nervous and forget things at your meeting, you can also make a tape recording of the things you want and bring the tape to play at the meeting.

Before the meeting, if you want, you can ask the regional center to test you—to learn the things you can do and the things you still need help with.

You can invite anyone to *your* IPP meeting. It's *your* meeting so if you want a friend, family member or advocate there to support you, ask them to come.

It is important that you strongly ask for the services you want—but don't get mad. It is always better to try to work together. But, it is *your* IPP and you have a right to ask for the services you think you need. Nobody else can do that as well as you can.

At the meeting, give your case manager or social worker the written list (or the tape) of your dreams and the services and help you want from the regional center. What you have written will help your case manager write your IPP.

**WHAT ARE SOME OF THE SERVICES AND HELP
YOU CAN ASK TO HAVE IN YOUR IPP?**

(At the very end of this booklet, there is a detailed list of services
you may request in your IPP. This list is taken from the Lanterman
Act, but the law does not limit you simply to the listed services —
that is, you may ask for any other services that will help you be
more independent or productive.

Help to get a job, including supported employment
services.

Help to get into a school or training program.

Transportation and help to learn how to use buses.

Instruction and support so that you can live in your own
place.

Training in how to advocate for yourself better.

Help to get involved in fun things going on in the
community.

Someone to assist you if you want to be on a committee or
a member of a board of directors and need help.

Help to get equipment like wheelchairs or computers that
talk.

Other services you need to live a better life.

WHAT DO YOU DO IF THE REGIONAL CENTER SAYS "NO" TO WHAT YOU WANT OR MAKES A CHANGE IN YOUR SERVICES THAT YOU DON'T LIKE?

If you are unhappy about a decision the regional center has made about services you want, you have a right to appeal the regional center's decision.

You should get people to help you with all the things involved with the appeal. It's not easy but it is your right to try to change the regional center's decision. It's in the law.

Within 5 days of making its decision, the regional center must send you a written letter about anything they are changing in your IPP services and tell you why.

If you don't understand the letter, get a friend or advocate to help you.

The regional center is supposed to tell you how to appeal in the letter. If they don't, you will have to ask them. Then you have to fill out a form and send it back.

If you send in a request for appeal within 10 days of the regional center's decision, the regional center cannot stop giving you a service while the appeal is going on. That is the law.

After you send in the appeal form, a meeting will be scheduled so you can again tell the regional center what you want and why you don't like what they decided.

After this meeting, if the regional center still doesn't agree to what you think should be in your IPP, you can ask for a fair hearing. At a fair hearing, you will have a chance to put your case before a hearing officer from the state. The hearing officer will decide if you get the service.

Remember, all this is complicated and everyone should get help with an appeal. Talk with your area board or Protection and Advocacy (telephone 1-800-776-5746) or People First for help.

Chapter 4

WHAT ARE YOUR RIGHTS IF YOU LIVE IN A BOARD AND CARE HOME?

Board and care homes must let you make decisions in your day-to-day life like:

When you go to bed

When you eat

Whether you want to have friends over, and

What you do in your free time.

If you live in a board and care home you also have a right to:

Wear your own clothes

Have your own things & use them

Keep and spend a reasonable amount of your own money

See visitors each day

Have a place to keep your own things

Talk on the phone

Mail and receive unopened letters and have letter writing materials including stamps

Rights can be taken away only if you would hurt yourself, another person or the home. Rights cannot be taken away to punish you.

If a right has been taken away, it must be reviewed every 30 days.

You can appeal the fact that a right has been taken away.

You start by calling the regional center's client's rights advocate.

You can also call the area board, Protection and Advocacy (1-800-776-5746) or People First for help.

Chapter 4

IPP MEETING PLANNER

This worksheet is to help you plan for the services you want to ask for from the regional center. Use it to help you think about the services you need to help you do all of the things you want to do.

A PLACE TO LIVE

Where do you live now?

☐ My own place
☐ My own place with
    roommates
☐ My parent's place

☐ A group home
☐ A large care facility
☐ Other _____

Where do you want to live?

☐ Stay where I am
☐ My own place
☐ My own place with
    roommates

☐ My parent's place
☐ A group home
☐ A large care facility
☐ Other _____

What services do you need to help you live where you want?

More training
☐ An attendant
☐ Someone to give me regular
☐ support and help

More money
☐ Help finding a place to live
☐ Other _____
☐

A *PLACE TO WORK*

Where do you work now?

- ☐ In the community without extra help
- ☐ In the community with a trainer or aid
- ☐ In a workshop or center
     go to school
- ☐ Don't work or go to school
- ☐ Other _____

Where do you want to work?

- ☐ In the community
- ☐ In a workshop or center
- ☐ I want to go to school
- ☐ I don't want to work
- ☐ Other _____

What services do you need to help you work?

- ☐ A trainer or aid at the job
- ☐ Training in a workshop
- ☐ Other training
- ☐ More education
- ☐ Access to workplace—ramps, etc.
- ☐ Transportation
- ☐ Other _____

Where do you want to work?
- ☐ Doctor Services
- ☐ Dentist Services
- ☐ Counseling

FUN AND LEISURE

What do you do for fun or with your free time?

- ☐ Visit friends
- ☐ Shop
- ☐ Go to movies or plays
- ☐ Play sports
- ☐ Hobby
- ☐ Watch TV

- ☐ Read
- ☐ Take classes
- ☐ Volunteer work
- ☐ Listen to music
- ☐ Dating
- ☐ Other _____

What new things do you want to do?

- ☐ Visit friends
- ☐ Shop
- ☐ Go to movies or plays
- ☐ Play sports
- ☐ Hobby
- ☐ Watch TV

- ☐ Read
- ☐ Take classes
- ☐ Volunteer work
- ☐ Listen to music
- ☐ Dating
- ☐ Other _____

What services do you need to help you do the things you want to do?

- ☐ Training
- ☐ Attendant
- ☐ Facilitator
- ☐ Transportation
- ☐ Set up a circle of friends
- ☐ Other_____

OTHER THINGS

What other things do you think you need help with?

- ☐ Cooking for myself
- ☐ Shopping for things I need
- ☐ Personal care
- ☐ Cleaning my place
- ☐ Managing my money
- ☐ Getting medical care
- ☐ Meeting more people/making friends
- ☐ Riding the bus or other transportation
- ☐ Learning about personal relationships
- ☐ Learning about sexual relationships and safe sex
- ☐ Self advocacy and knowing my legal rights
- ☐ Problems with social security, SSI or other money assistance programs
- ☐ Other _____

What other services do you need to help with these things?

- ☐ Training (what type ? _____)
- ☐ An attendant
- ☐ A chore worker
- ☐ Just someone to ask questions to
- ☐ Help setting up a circle of friends
- ☐ An advocate or lawyer
- ☐ A service coordinator to help me plan for and get services I need
- ☐ Other _____

REGIONAL CENTER SERVICES

Services and supports listed in the individual program plan may include, but are not limited to:

diagnosis;

evaluation;

treatment;

personal care;

day care;

domiciliary care;

special living arrangements;

physical, occupational, and speech therapy;

training;

education;

supported and sheltered employment;

mental health services;

recreation;

counseling of the individual with a developmental disability and of his or her family;

protective and other social and sociolegal services;

information and referral services;

follow-along services;

adaptive equipment and supplies;

advocacy assistance, including self-advocacy training, facilitation and peer advocates;

assessment;

assistance in locating a home;

childcare;

behavior training and behavior modification programs;

camping;

community integration services;

community support;

daily living skills training;

emergency and crisis intervention;

facilitating circles of support;

habilitation;

homemaker services;

infant stimulation programs;

paid roommates;

paid neighbors;

respite;

short term out-of-home care;

social skills training;

specialized medical and dental care;

supported living arrangements;

technical and financial assistance;

travel training;

training for parents of children with developmental disabilities;

training for parents with developmental disabilities;

vouchers;

transportation services necessary to ensure delivery of services to persons with developmental disabilities.

GETTING THERE
FROM HERE!

Tips on the Person-Centered
Planning Process
Used by HRC Counselors

Harbor Regional Center

21231 Hawthorne Blvd., Torrance, CA 90503, (310) 540-1711

11/92

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Tips on the Person-Centered Planning Process

Introduction

Over the last five years or so, there's been a shift in services for people with developmental disabilities and their families (Bradley & Knoll, 1990). It used to be that services helped separate people from their communities. These days, we're all working hard to find ways to support people in the places where they already live, work and play. This means that as a regional center we need to support people with developmental disabilities and their families in ways that lead to:

- Community membership;

- A person-centered plan;

- Choice and self-determination;

- A commitment to community and family; and,

- Social relationships.

That's what this planning process is all about, helping people look at their hopes and dreams for the future, figuring out the support they need (from family, friends, community and agencies) to get there, and then writing down some first steps to take to move towards that plan right now.

In this guide you'll find some background information on person-centered planning and tips on using all three of the interview formats *(Families of Young Children, Families of Students, Looking at Adult Life)*.

Tips on the Person-Centered Planning Process

An Excerpt from *The Challenger*
ARC-Napa Newsletter October 1991

Frustrated by traditional IEP or IPP meetings? Concerned with overemphasis on deficiencies? Wonder why many professionals don't want to talk about the things most important to you and your family? Feel there must be a better way?

Well, you're not alone! And, you are right. There is a better way. Person-centered planning involves a new way of thinking about a person with a disability, and helping that person lead a more fulfilling life. Person-centered planning is a variant of personal futures planning (Beth Mount), lifestyle planning (John O'Brien and Connie Lyle), and MAPS (Marsha Forest).

The approach is to develop a vision of a desired future, based on who the person with a disability wants to be and to do, and then to marshal resources to support the person in achieving his or her goals. The circle-of-support or person-centered team seeks to develop community connections, to invent and experiment with novel courses of action, and to stand by the person as any close friend would do.

The traditional way of planning services relies on (1) assessments that look at 'deficits' rather than gifts and strengths; (2) using professional judgment in the place of what the individual and his or her family know about themselves; (3) efforts to 'fix' people, to get ready (often indefinitely) for life; and (4) opportunities, defined by what exists rather than what is wanted. This is service-centered planning, and combined with high case loads, budget constraints, and restricted service menus, often produces mismatches.

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Tips on the Person-Centered Planning Process

An analogy may help. Mr. Jones has a leaky faucet, calls a plumber, and she comes to his house to install a water heater. At first, he passes it off as a misunderstanding. The water heater didn't cost him anything, and although he had to fix the faucet himself, he ends up with a sparkling new water heater. Sometime later, Mr. Jones has a leaky toilet, and again calls the plumber. She decides that he really needs another water heater, and installs it. Finally, Mr. Jones throws up his hands, and turns elsewhere for help.

We recently compared the plans generated for a young woman we support. In 1989, Mary's IPP listed four objectives, as follows:

- *With supervision, increase her work skills and productivity;*

- *With monitoring, Mary completes household responsibilities on a regular basis;*

- *Following a budget, Mary pays her bills and buys personal items with money allocated on a weekly basis; and*

- *With support services, Mary socializes in the community with peers at least once a month.*

Mary's person-centered plan, worked out at about the same time, listed Mary's objectives as follows:

- *A job at Mervyns;*

- *Learning communication and problem-solving skills that will help in her relationship with Stan;*

- *The chance to spend time with Stan, so they can find out more about each other as they move towards marriage;*

Tips on the Person-Centered Planning Process

- *Learn about pregnancy and raising a child;*

- *Change her relationship with her mother from adult I child to adult / adult; and*

- *Make sure she keeps her apartment.*

Wouldn't it be more fun to approach life this way[1]? And, wouldn't we contribute more to the well-being of those we care about? We think so!

Selected Excerpts from
It's Never Too Early
It's Never Too Late
Written by Beth Mount and Kay Zwernick

New Possibilities

Human services should provide a bridge to the community for people with disabilities. Building on people's capacities and opportunities in networks and communities allows desirable futures to be created and supported. This is the aim *of Personal Futures Planning.*

A New Way to Plan Together

Implementing these new values and accomplishing new outcomes means letting go of service practices that support the old assumptions. For example, the traditional approach to planning for people with disabilities is focused on deficit-finding. This deficit-finding is cumulative as it continues year after year. For each skill a person acquires and each objective a person meets, new deficits are identified and new goals developed. The traditional Individual (Service) Plan process often ends up justifying the continuance of deficit-finding and devaluation in the lives of people with handicaps.

Tips on the Person-Centered Planning Process

There are at least three major problems with the traditional approach to planning:

1. It begins with an assessment process that often highlights the person's deficits. When the person is defined in terms of deficits, then the person is in constant need of services and "fixing." In this situation, the person is never ready for community life.

2. It tends to establish goals that are already part of existing programs. The plan is designed to fit the person into a particular program, even if that program is not exactly what that person needs.

3. It relies solely on professional judgment and decision-making. People with disabilities are prevented from taking initiative or directing action to affect their own lives.

The shortcomings of the ISP can be counterbalanced with a *Personal Futures Plan* developed for the focus person. The ultimate goal of both planning strategies is to improve the quality of life for the person with a disability.

What's person-centered planning all about?

"Personal Futures Planning provides strategies to increase the likelihood that people with disabilities will develop relationships, be part of community life, increase their control over their lives, acquire increasingly positive roles in community life and develop competencies to help them accomplish these goals. Futures planning helps to clarify and implement these ideals, one person at a time."

<div style="text-align: right">

Beth Mount
Kay Zwernik
It's Never Too Early
It's Never Too Late

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Tips on the Person-Centered Planning Process

Person-centered planning (adapted from *Personal Futures Planning)* is a process which complements and enhances traditional service planning. Traditional approaches and plans are often restricted by:

- The service options that a particular agency offers; and,

- The current bureaucratic categories, laws and/or state politics.

This planning tool, like any other, is only as good as the people who use it to take action. It will have a greater chance for success when:

- The group focuses on strengths, preferences and opportunity;

- The picture of the future is detailed and specific;

- People commit to meet on a regular basis and stick to their commitments of support when they make them;

- Someone agrees to facilitate the meeting to keep the group focused;

- People participating are well connected to their community; and,

- Family members and advocates are in the group.

In using the process, it's important to ask questions in a way that doesn't limit thinking about individual options. This strategy is built on the following assumptions:

1. All things are possible with the right types of support;

2. Support can come from all parts of the community, e.g., parents, family, friends, generic services;

3. Presenting a 'fixed' menu of service options will produce 'fixed' outcomes, not necessarily based on individual preferences;

4. Given lead time, support services can adapt to individual preferences or new support service options can be created; and,

Chapter 4

Tips on the Person-Centered Planning Process

5. Most important, that we will not know how to plan for the future unless we ask people with disabilities and their families what it will look like.

The value basis for person-centered planning includes:

- Service options that are based on choices, strengths and needs (rather than a predetermined 'menu');

- Service delivery (type and intensity) that varies from time to time as do strengths and needs (rather than providing more than what is needed or something that is not needed);

- Access to resources that are readily available in the community (not developing new services for persons with disabilities only);

- Services that are coordinated around individual needs (rather than the needs of staff and services); and

- Recognizing the abilities of friends, families, co-workers to teach new skills, participate with, model social behavior and to develop relationships.

The complete set of questions used in Personal Futures Planning (originally developed by Beth Mount and adapted by Alien, Shea & Associates for Harbor Regional Center) is as follows:

Personal Profile:

1. Who is this about?

2. Who helped make this plan?

3. What services do I get now from agencies?

4. How do they describe me?

Tips on the Person-Centered Planning Process

5. What is my health status?

   A. What health supports do I use now?

6. What are the highlights of my life?

7. Who are the people I know?

8. What do people think of me? (things that are good and bad)

9. What places do I go?

10. What things make me happy and sad?

11. What new people would I like to meet?

12. What things have I learned recently?

13. What new things would I like to do and learn? (What new places would I like to go?)

14. What scares me most about my future?

15. What jobs have I had?

16. What jobs would I like to try?

17. What other things do I know?

18. What is fun about the jobs I have had or would like to try?

19. What would I like about these jobs?

Personal Vision:

20. If I could do anything I wanted, what would my best possible future be?

21. What would I need to know, or what would need to happen to make this possible? People? Community? Systems?

Tips on the Person-Centered Planning Process

Person-Centered Plan:

22. Moving toward that vision, what do I want to work on during the next year?

23. What would I need to know, or what would need to happen to make this possible? People? Community? Systems?

Families of Young Children

1.

HOW TO GET THERE FROM HERE!
Families of Young Children

What's this all about? This is a chance for families and friends of young children with disabilities to sit down and think about where they're going in the future and the support that they might need to get there. The map will help you to start working towards your hopes and dreams right now. It will also help us at Harbor Regional Center get an idea of where we fit into your lives. It was written to be used in several ways: (1) you can fill it out by yourself; or (2) you can work on it with your counselor or case manager. This is not something you have to do, it's voluntary. However, we think that you'll find it useful as well as fun!

1 **What is your son's or daughter's name?** 2.   3.

2 **Who's in your son's or daughter's circle of support? Mom and dad? Family? Others? Who supports you and your son or daughter when you need it?**

4.

Your son or daughter
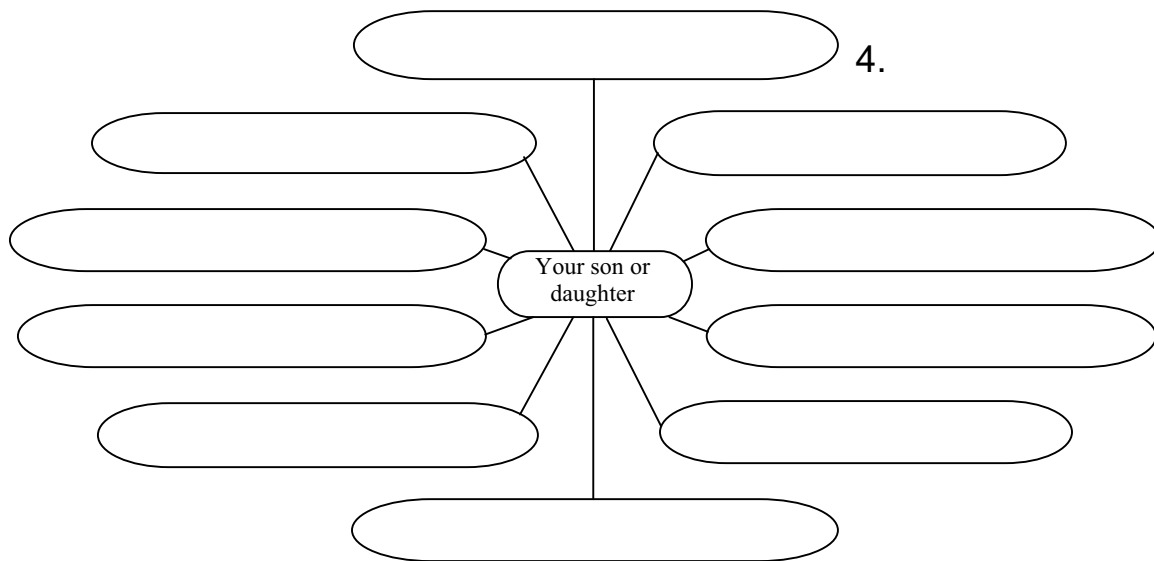
3 **What are some of the great things about your son or daughter?**

5.

6.

Adapted from *Personal Futures Planning* (Mount) and *Parent Assessment of Needs* (Chen, Friedman, Calvello)
(or R.C.E.B. and H.R.C. by Alien, Shea & Associates; revised 4/92).

Notes and Tips

1. All three of the interview formats have been written in accessible

Families of Young Children

language. This allows for a lot of variation in use: you can send out the interview format ahead of time; people can fill it out on their own and go over it with you later; or, you can meet and go through the interview together. Deciding when to use this interview is really up to you and the people you are working with at the time. You might decide to use it at a transition time (e.g., leaving school, going to school, leaving home, moving from one place to another). You can choose to review it each year or wait until the triannual IPP review.

2. The focus person of the interview.

3. Who sits in on this interview and where the interview is held are very important. The most ideal situation is to include everyone who can help support someone in looking ahead. This may mean family, friends or other professionals and it may not. The only way to find out is to ask! The interview should be held wherever it's most comfortable for the person interviewed. This could mean a restaurant or someone's house.

4. This will help you get a picture of someone's circle of support.

5. This is an opportunity to set the positive tone for this interview.

6. The *rule of thumb* is to ask the question of the focus person first and then ask others to contribute. It's a good idea to mark the comments of the focus person (e.g., with an asterisk). It's also a good idea to have a focus person in attendance even if he/she cannot communicate. This helps everyone keep thinking positively and of the person first, their disability second.

It's suggested that you use this interview format *(Families of Young Children)* for children under 5 years of age. For families of very young children, especially those who are very new to the service system or for

Families of Young Children

HOW TO GET THERE FROM HERE!
Families of Young Children

What kinds of things does your child do on his or her own or with your support? at home? around town? for fun?

7.

5

What new things would you like your child to learn to do on his or her own or with your support? at home? around town? for fun?

8.

6

What makes your son or daughter happy?

9.

7

What makes your son or daughter mad or sad or frustrated?

10.

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whom major life crises are occurring, this may not seem to be appropriate. As counselors, you know the families that you work with the best and can make a decision as to when such an interview would be helpful.

7. This is a chance to find out a little more about a child's and family's community boundaries.

Families of Young Children

8. At this point in the interview, you're getting everyone ready to start thinking about the future. Try to keep this discussion going as long as possible!

> These are not questions that people with disabilities are often asked by anyone. So, don't be surprised if you don't get a lot of information the first couple of times that you ask. It's okay! You may need to remind people that it's okay to have dreams and hopes about the future. Sometimes, it's what keeps us going.

9. This question helps keep the interview fun and light. If you're not having fun, it's not likely anyone else is enjoying themselves. Take a minute to just talk if needed.

10. This can help clarify *barriers* in current and future living, social and working environments, e.g., skill needs, attitudes, fear of the unknown.

Families of Young Children

HOW TO GET THERE FROM HERE!

8 What activities do you or other family members like to do with your son or daughter? 11.	**9** Are there some things that your child could do to make a difference in your family life? 12.
10 Are there questions or concerns that you have that haven't been answered? 13.	What scares you or other family members the most—right now, and in the future for your son or daughter?
12 What kinds of support does your son or daughter, and your family need? 14.	**13** Who can help support you? How?

14 Who helped work on this? 15.

11. We're still focusing on preferences and strengths, which will help people think positively about the future.

12. Now the interview starts to focus both on planning for the future and thinking about things that will help right now.

Families of Young Children

13. This is a time to find out what worries families about the future. This is very important to know when you're working with persons who are about ready to make a major life change (like from home to preschool).

14. This starts bringing things back to right now and leads to developing some first steps towards implementing a person-centered plan.

    Remember that support here is not just a service from the regional center, it could mean support from family or friends or services that don't even exist at this time!

15. Who helped provide the information for this interview.

Families of Young Children

Name of Person:	Harbor Regional Center *Bringing It All Together!*		UCI Number:
Moving towards the future, what do you hope will happen next for your son or daughter?	What kinds of support will you need from:		
	Family, friends and community	Support service agencies	
16.	17.		
How will you know if your plan has worked? 18.			

16. At this time, the discussion turns to developing next step plans in moving towards the future. Plans can include activities, information, advocacy, skill building and support services.

17. Everyone can be a part of the plan. In fact, this is a good time to start thinking about natural supports. The regional center is just one of many support service agencies in the community.

18. Asking families and friends to develop an evaluation plan helps everyone take some responsibility for it. Everyone has a different criteria for success and it's important to find out what that is early on in the planning process.

Families of Young Children

HOW TO GET THERE FROM HERE!
Other Notes

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Notes and Tips

This page can be used as an insert for your additional notes on any one item during the inter

Families of Students

	HOW TO GET THERE FROM HERE!
1.	**Families of Students**

What's this all about? This is a chance for students with disabilities and their families and friends to sit down and think about where they're going in the future and the support that they might need to get there. This *map* will help you to start working towards your hopes and dreams right now. It will also help us at Harbor Regional Center get an idea of where we fit into your lives. It was written to be used in several ways: (1) you can fill it out by yourself; (2) someone can ask you the questions and write down your answers; (3) you can work on it with your counselor or case manager; or (4) family and friends can fill it out if you need help in answering. This is not something you have to do, it's *voluntary.* However, we think that you'll find it useful as well as fun!

1   **Who is this about?**   2.   3.

2   **Who's on your team? Who helps or supports you? Who are your friends? Who do you turn to for help when you need it?**

4.

Student

Chapter 4

3

   hat are some of the *great things* about you?

5.

6.

Families of Students

Notes and Tips

1. All three of the interview formats have been written in accessible language. This allows for a lot of variation in use: you can send out the interview format ahead of time; people can fill it out on their own and go over it with you later; or, you can meet and go through the interview together. Deciding when to use this interview is really up to you and the people you are working with at the time. You might decide to use it at a transition time (e.g., leaving school, going to school, leaving home, moving from one place to another). You can choose to review it each year or wait until the triannual IPP review.

2. The focus person of the interview.

3. Who sits in on this interview and where the interview is held are very important. The most ideal situation is to include everyone who can help support someone in looking ahead. This may mean family, friends or other professionals and it may not. The only way to find out is to ask! The interview should be held wherever it's most comfortable for the person interviewed. This could mean a restaurant or someone's house.

4. This will help you get a picture of someone's circle of support.

5. This is an opportunity to set the positive tone for this interview.

6. The *rule of thumb* is to ask the question of the focus person first and then ask others to contribute. It's a good idea to mark the comments of the focus person (e.g., with an asterisk). It's also a good idea to have a focus person in attendance even if he/she cannot communicate. This helps everyone keep thinking positively and of the person first, their disability second.

   It's suggested that you use this interview format *(Families of Students)* for children and young adults who are school students.

Families of Students

HOW TO GET THERE FROM HERE!

4 **What things do you like to do? at home? around town? for fun?**

7.

5 **What new things would you like to learn how to do? at home? around town? for fun?**

8.

6 **What makes you happy?**

9

7 **What makes you mad or sad or frustrated?**

10.

7. This is a chance to find out a little more about someone's community boundaries, likes and dislikes and could help in looking at places to live and work. You might also ask how people get where they go and who goes with them.

If you feel that someone has trouble talking in a group or that it will add to your information base, consider interviewing him/her apart from family, friends or other professionals.

Families of Students

8. At this point in the interview, you're getting everyone ready to start thinking about the future. Try to keep this discussion going as long as possible!

   These are not questions that people with disabilities are often asked by anyone. So, don't be surprised if you don't get a lot of information the first couple of times that you ask. It's okay! You may need to remind people that it's okay to have dreams and hopes about the future. Sometimes, it's what keeps us going.

9. This question helps keep the interview fun and light. If you're not having fun, it's not likely anyone else is enjoying themselves. Take a minute to just talk if needed.

10. This can help clarify *barriers* in current and future living, social and working environments, e.g., skill needs, attitudes, fear of the unknown.

Families of Students

HOW TO GET THERE FROM HERE!
At School

8 **What new things have you learned at school in the last year?**

11.

9 **What new things would you like to learn at school?**

10 **If you're learning about work, what jobs have you had?**

12.

11 **If you're learning about work, what jobs would you like to try?**

12 **What's the best part about your Individual Education Plan and your school for you?**

13.

13 **What could be better about your Individual Education Plan and your school for you?**

Families of Students

11. These questions will help you continue building to dreams and hopes for the future. They will also give everyone ideas about future goals and objectives for the Individual Education Plan (IEP). Offer to provide a copy of your notes on this interview to whomever is interested with permission from the person you're interviewing.

12. These two questions could give you some leads about current and future employment preferences, goals and objectives.

13. These two questions can provide a basis for support of the education plan as well as prompts regarding potential areas for educational advocacy.

Families of Students

HOW TO GET THERE FROM HERE!
Looking Ahead

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14 **What are your dreams and hopes for the future?**

14.

15 **What scares you the most about your future?**

15.

16 **What do you see yourself doing in 3-5 years?**

16.

17 **What support would you need to get there?**

17.

18 **Who can help you with that support? How?**

18.

19 **Who helped work on this?**

19.

14. What would be the best future? There are no right or wrong answers! You may need to remind people that everything is possible and that this is a chance to dream about what could be!

15. This is a time to find out what worries people with disabilities and their families and friends about the future. This is very important to

Families of Students

know when you're working with persons who are about ready to make a major life change (like moving out of their family home).

16. This starts bringing things back to right now and leads to developing some first steps towards implementing a person-centered plan.

17. Remember that support here is not just a service from the regional center, it could mean support from family or friends or services that don't even exist at this time!

    You may need to remind people that everything is possible and that this is a chance to dream about what could be! Let this part of the interview go as long as you can! It will provide everyone with a lot of ideas about the future and about what they might just do right now!

18. This helps reinforce everyone working together as a team when support is needed.

    If you're working with a circle of support, you might want to suggest that you all get together again soon to start moving towards the best possible future.

19. Who helped provide the information for this interview.

Families of Students

20 Name of Person	Harbor Regional Center *Bringing It All Together!*	UCI Number
Moving towards your plan for the future, what do you hope will happen next?	What kinds of support will you need from	
	Family, friends and community	Support service agencies
20.	21.	
How will you know if your plan has worked?		
22.		

20. At this time, the discussion turns to developing next step plans in moving towards the future. Plans can include activities, information, advocacy, skill building and support services.

21. Everyone can be a part of the plan. In fact, this is a good time to start thinking about natural supports. The regional center is just one of many support service agencies in the community.

22. Asking people with disabilities and their families and friends to develop an evaluation plan helps everyone take some responsibility for it. Everyone has a different criteria for success and it's important to find out what that is early on in the planning process.

Chapter 4

Families of Students

HOW TO GET THERE FROM HERE!
Other Notes

This page can be used as an insert for your additional notes on any one item during the interview.

Families of Students

HOW TO GET THERE FROM HERE!
Things About How You Live and Would Like to Live

How do you live now?

Alone? ☐
With a roommate? ☐
With your parents? ☐
With other relatives? ☐
In a group home? ☐
Other? ☐

What do you see as the best *things* about where you live right now?

What do you see as the *biggest* challenges of where you live right now

All things possible, where would you like to live and with whom?

Are you living where you want to live and with whom you want to live?

What kinds of support do you need where you live right now?

If you're living where you want to live for now, please go to question #19.

Chapter 4

This page can be used as insert for individuals who are school-aged and living in other than the home of their parents. These questions will help you to continue building dreams and hopes for the future. They will also give everyone ideas about support needs for living and new options to explore.

Families of Students

HOW TO GET THERE FROM HERE!
Looking Forward to Your Next Transition

The questions on these two pages are designed to help you bring together your thoughts about a transition strategy for your son and daughter and some first steps to take towards realizing the *best possible future* after that transition. Remember, this is your plan and it may not be the plan that your son or daughter has in mind so you need to have a family discussion about it as soon as you can. This strategy planning process is built on the following values: 1) all things are possible with the right types of support; 2) support can come from all parts of the community, e.g., parents, family, friends, community services; 3) given lead time, support services can adapt to individual preferences or new support service options can be created; and, 4) most important, that we won't know how to plan for the future unless we ask people with disabilities and their families what it will look like.

1 Who is this about?

2 What's the next transition for your son or daughter and family?

3 All things possible, what would life look like for your son or daughter after that transition?

4 What kinds of support do you think your son or daughter and family would need to make that transition a smooth one?

5 What worries you the most about that next transition?

6 What are some first steps that you could take to start moving your son or daughter and family towards that next transition?

Families of Students

This is a two-page focus interview on transition which can be used as an insert for families of young children and families of students or when talking to adults who will be experiencing some sort of transition within the next year. The transition might be from school to school, from home to home, from school to adult services and so on. It really helps focus activities and information on things that will help make for a smooth transition for everyone involved.

Looking at Adult Life

HOW TO GET THERE FROM HERE!
1.   **Looking at Adult Life**

What's this all about? This is a chance for people with disabilities and their families and friends to sit down and think about where they're going in the future and the support that they might need to get there. This *map* will help you to start working towards your hopes and dreams right now. It will also help us at Harbor Regional Center get an idea of where we fit into your lives. It was written to be used in several ways: (1) you can fill it out by yourself; (2) someone can ask you the questions and write down your answers; (3) you can work on it with your counselor or case manager; or (4) family and friends can fill it out if you need help in answering. This is not something you have to do, it's *voluntary.* However, we think that you'll find it useful as well as fun!

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1   **Who is this about?**   2.   3.

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2   **Who's on your team? Who helps or supports you? Who are your friends? Who do you turn to for help when you need it?**

4.

Student

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3   **What are some *great things* about you?**

5.

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Adapted from *Personal Futures Planning* (Mount) for R.C.E.B. and H.R.C. by Alien, Shea & Associates; revised 4/92.

Notes and Tips

1. All three of the interview formats have been written in accessible

Looking at Adult Life

language. This allows for a lot of variation in use: you can send out the interview format ahead of time; people can fill it out on their own and go over it with you later; or, you can meet and go through the interview together. Deciding when to use this interview is really up to you and the people you are working with at the time. You might decide to use it at a transition time (e.g., leaving school, going to school, leaving home, moving from one place to another). You can choose to review it each year or wait until the triannual IPP review.

2. The focus person of the interview.

3. Who sits in on this interview and where the interview is held are very important. The most ideal situation is to include everyone who can help support someone in looking ahead. This may mean family, friends or other professionals and it may not. The only way to find out is to ask! The interview should be held wherever it's most comfortable for the person interviewed. This could mean a restaurant or someone's house.

4. This will help you get a picture of someone's circle of support.

5. This is an opportunity to set the positive tone for this interview.

6. The *rule of thumb* is to ask the question of the focus person first and then ask others to contribute. It's a good idea to mark the comments of the focus person (e.g., with an asterisk). It's also a good idea to have a focus person in attendance even if he/she cannot communicate. This helps everyone keep thinking positively and of the person first, their disability second. It's suggested that you use this interview format *(Looking at Adult Life)* for anyone who is no longer a student.

Chapter 4

Looking at Adult Life

HOW TO GET THERE FROM HERE!

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4   **What things do you like to do? around town? at home? for fun?**

7.

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5   **What new things would you like to do? around town? at home? for fun?**

8.

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6   **What makes you happy?**

9

7   **What makes you mad or sad or frustrated?**

10.

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7. This is a chance to find out a little more about someone's community boundaries, likes and dislikes and could help in looking at places to live and work. You might also ask how people get where they go and who goes with them.

If you feel that someone has trouble talking in a group or that it will add to your information base, consider interviewing him/her apart from family, friends or other professionals.

Looking at Adult Life

8. At this point in the interview, you're getting everyone ready to start thinking about the future. Try to keep this discussion going as long as possible!

   These are not questions that people with disabilities are often asked by anyone. So, don't be surprised if you don't get a lot of information the first couple of times that you ask. It's okay! You may need to remind people that it's okay to have dreams and hopes about the future. Sometimes, it's what keeps us going.

9. This question helps keep the interview fun and light. If you're not having fun, it's not likely anyone else is enjoying themselves. Take a minute to just talk if needed.

10. This can help clarify barriers in current and future living, social and working environments, e.g., skill needs, attitudes, fear of the unknown.

Looking at Adult Life

HOW TO GET THERE FROM HERE!
About Work

9 If you're not working right now, what do you do during the day?

12.

9 If you're interested in working, what jobs have you had?

If you're not interested in working, please turn to the page called *Things About How You Live and Would Like to Live.* If you're already working, please go to question #12.

10 If you're interested in working, what kinds of jobs interest you?

11 Do you need support in getting a job?

Are you looking for your

| first job? | __Yes | __No |

Does it take you a long time to

| learn a job? | __Yes | __No |

Do you get social security

| benefits? | __Yes | __No |

Do you need support in things like using money or getting

| to work? | __Yes | __No |

If you answered yes to any of these questions, you could probably use some support in getting and keeping a job.

Already Working, How's Your Job?

Is it the kind of job you like?	__Yes __No
Are the hours and days okay?	__Yes __No
Do you get the support you need?	__Yes __No
Does the pay cover your bills?	__Yes __No
Do you get benefits?	__Yes __No

How do you get along with people at work?

__great
__okay
__not very well

13. When you think about your job (check the one that shows how you feel most of the time)

__Are you glad you got it? _
__It's okay that you got it
__You're sorry that you got it

Looking at Adult Life

11. These questions will help you continue building dreams and hopes for the future. They will also give everyone ideas about support needs for working and new options to explore.

    Offer to provide a copy of your notes on this interview to whomever is interested, with permission from the person you're interviewing.

12. These two questions could give you some leads about supported employment options.

13. If you get some **no** answers, this information could be used to facilitate employment advocacy.

Chapter 4

Looking at Adult Life

HOW TO GET THERE FROM HERE!
Things About How You Live and Would Like to Live

13 How do you live now?

14.

14 What do you see as the *best things* about where you live right now?

15.

15 What do you see as the *biggest challenges* of where you live right now?

16 What kinds of support do you need where you live right now?

17 Are you living where you want to live and with whom you want to live?

If you're living where you want to live for now, please go to question #19.

18 All things possible, where would you like to live and with whom?

.

14. These questions will help you continue building to dreams and hopes for the future. They will also give everyone ideas about support needs for living and new options to explore.

15. This page is also available with no interview question numbers. In this way, it can be used as an insert for individuals who are school-aged and living in other than the home of their parents.

Looking at Adult Life

HOW TO GET THERE FROM HERE!
Looking Ahead

19

What are your dreams and hopes for the future?

16.

20

What scares you the most about your future?

17.

---

16. What would be the best future? There are no right or wrong answers!

You may need to remind people that everything is possible and that this is a chance to dream about what could be!

Looking at Adult Life

17. This is a time to find out what worries people with disabilities and their families and friends about the future. This is very important to know when you're working with persons who are about ready to make a major life change (like moving out of their family home).

HOW TO GET THERE FROM HERE!
Looking Ahead

---

21   **What do you see yourself doing in 3-5 years?**

18.

22   **What support would you need to get there?**

19.

23   **Who can help you with that support? How?**

20.

24   **Who worked on this plan?**

21.

Looking at Adult Life

18. This starts bringing things back to right now and leads to developing some first steps towards implementing a person-centered plan.

19. Remember that support here is not just a service from the regional center, it could mean support from family or friends or services that don't even exist at this time!

    You may need to remind people that everything is possible and that this is a chance to dream about what could be! Let this part of the interview go as long as you can! It will provide everyone with a lot of ideas about the future and about what they might just do right now!

20. This helps reinforce everyone working together as a team when support is needed.

    If you're working with a circle of support, you might want to suggest that you all get together again soon to start moving towards the best possible future.

21. Who helped provide the information for this interview.

Looking at Adult Life

25 **Name of Person**	Harbor Regional Center Bringing It All Together!	**UCI Number**
Moving towards your plan for the future, what do you hope will happen next?	**What kinds of support will you need from**	
	Family, friends and community	**Support service agencies**
22.	23.	
How will you know if your plan has worked? 24.		

22. At this time, the discussion turns to developing next step plans in moving towards the future. Plans can include activities, information, advocacy, skill building and support services.

Looking at Adult Life

23. Everyone can be a part of the plan. In fact, this is a good time to start thinking about natural supports. The regional center is just one of many support service agencies in the community.

24. Asking people with disabilities and their families and friends to develop an evaluation plan helps everyone take some responsibility for it. Everyone has different criteria for success and it's important to find out what that is early on in the planning process.

Chapter 4

Looking at Adult Life

HOW TO GET THERE FROM HERE!
Other Notes

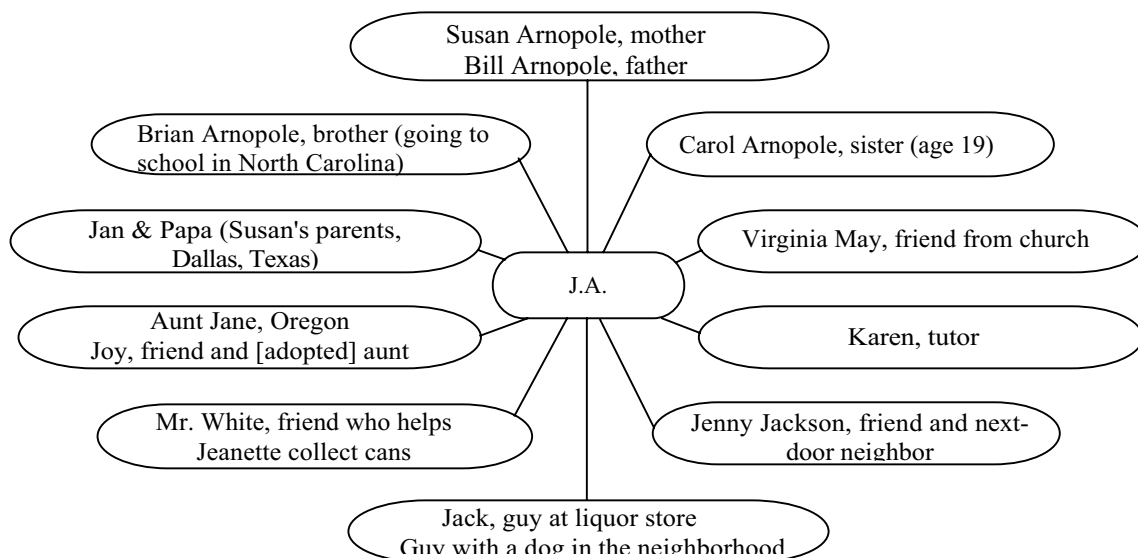This page can be used as an insert for your additional notes on any one item during the interview.

A Sample Interview

HOW TO GET THERE FROM HERE!
Looking at Adult Life

What's this all about? This is a chance for people with disabilities and their families and friends to sit down and think about where they're going in the future and the support that they might need to get there. This *map* will help you to start working towards your hopes and dreams right now. It will also help us at Harbor Eegional Center get an idea of where we fit into your lives. It was written to be used in several ways: (1) you can fill it out by yourself; (2) someone can ask you the questions and write down your answers; (3) you can work on it with your counselor or case manager; or (4) family and friends can fill it out if you need help in answering. This is not something you have to do, it's *voluntary.* However, we think that you'll find it useful as well as fun!

1   **Whose plan is this?** *Jeanette Arnopole, age 22*

2   **Who's on your team? Who helps or supports you? Who are your friends? Who do you turn to for help when you need it?**

Susan Arnopole, mother
Bill Arnopole, father

Brian Arnopole, brother (going to school in North Carolina)

Carol Arnopole, sister (age 19)

Jan & Papa (Susan's parents, Dallas, Texas)

Virginia May, friend from church

J.A.

Aunt Jane, Oregon
Joy, friend and [adopted] aunt

Karen, tutor

Mr. White, friend who helps Jeanette collect cans

Jenny Jackson, friend and next-door neighbor

Jack, guy at liquor store
Guy with a dog in the neighborhood

1   **What are some great things about you?** *Jeanette mentioned things she does, but not characteristics of her personality. Others, including parents, shared the following observations:*

Outgoing	Honest
Almost always happy	Dependable—If Rebecca says she will do
Plans ahead/likes to schedule things	something, she will follow through
Hard worker	Brave (taken airplane trips on own; learned buses)
Very independent	Plans activities
Concern for others/animals	Talks things through till comfortable
Makes people feel comfortable	Thoughtful (e.g., gifts, cards for friends)
Good with John, a neighbor's child	
(e.g., organized Easter Egg Hunt)	

A Sample Interview

HOW TO GET THERE FROM HERE!
Things About You

4 **What things do you like to do? around town? at home? for fun?**

Jeanette said:
Crush cans to make money (and later it was learned that this relaxes neck muscles and relieves tension)
Going for walk with dog in neighborhood

Others said:
Going out to eat
Talking with people
Talking with pets, and taking care of them (sister
  mentioned chasing bird in the bathroom, and
  getting it back in its cage)

Making pizza and other items
Games, such as parcheesi, Hearts, Jenga
Planning parties and giving them
Holidays (decorating, shopping, etc.)
Using coupons and shopping for groceries

5 **What new things would you like to do? around town? at home? for fun?**

Jeanette said:
A job, such as handing out coupons at a store

Others said:
Learn how to type/use computer
Doing crafts with sister
Helping at Humane Society as volunteer (this is in the works, currently)

6 **What makes you happy?**

Jeanette said:
Parties
Listening to music

Others said:
See old friends, etc.
Going out to eat
Jan, Papa, Brian coming to visit
Walking to store on own
Planning trips, parties, etc.

7 **What makes you mad or sad or frustrated?**

Jeanette said: Sometimes angry with sister
Dad telling her to be quiet, if he's watching TV

Others said: Sometimes loses cool Brother and sister doing things that she
  cannot do Seeing a dog in neighborhood chained and not
  being petted
The family dog (Toby) died When treated like a child If people say she is 'little'
If things are not ready on time; if people are late
If change is unanticipated, or not scheduled,
  or not announced
If she doesn't understand directions If she really wants to do something, and it is
  interrupted

A Sample Interview

HOW TO GET THERE FROM HERE!
About Work

8 If you're net working right now, what do you do during the day?

Jeanette said:
Crushing cans (about $8 per week)

Others said:
Takes up offerings at church Folds bulletins for Lutheran Church (pastor lives up the street)

9 If you're interested in working, what jobs have you had?

Jeanette said: See #8, above
Others said: See #8, above. Red Cross (volunteer couple of hours per week: rolling pennies; tidying paper; labels; ink stamps); Humane Society (volunteer couple hours per week: feeding, groom-ing, etc.); Convalescent Hospital (quit; couldn't understand what was wanted; staff not helping enough); Eden Express in San Pedro (dishes, ironing, folding napkins, etc.); JTPA/ROP job at Vet's Hospital (swept, napkins, towels, aprons, etc.; didn't like yard work); Work experience job (addressing at Special Services); Dollar Saver (delivering papers; stuffing envelopes); and, Pet Store (volunteer work: too confusing; too many different types of birds and of birdseed that needed to be matched, etc.)

10 If you're interested in working, what kinds of jobs interest you?

Jeanette said:
Animal care (feeding, watering, grooming, cleaning cages)

Others said:
In general, Jeanette likes working around people and animals, and her mother feels that Jeanette is best if there are breaks interspersed with more focused work.
Being a greeter at a party
Restaurant work is probably out (doesn't like it)
Messenger (e.g., delivering mail between offices in a complex)

11 Do you need support in getting a job?

Are you looking for your first job? X Yes
Does it take you a long time to learn a job? X Yes
Do you get social security benefits? X Yes
Do you need support in things like using money or getting to work? X No
Others said: Making change is sometimes difficult. Jeanette did well rolling pennies and didn't need close supervision. There was a discussion about whether supervisors/co-workers provide accurate, candid feedback as to their experience with Jeanette as a worker/volunteer. Julie, at ARC-Long Beach, is said to see a need for a lot of supervision. Others, including Jeanette's tutor, don't see it this way. Perhaps different supervisors report different things to family and Julie.

12 Already Working, How's Your Job?

Is it the kind of job you like?	__Yes
Are the hours and days okay?	__Yes
Do you get the support you need?	__Yes
Does the pay cover your bills?	__Yes
Do you get benefits?	__Yes

How do you get along with people at work?

—great __okay __not very well

— No When you think about your job (check the one that
— No shows how you feel most of the time)
__Are you glad you got it?
__ It's okay that you got it
__ You're sorry that you got it

A Sample Interview

HOW TO GET THERE FROM HERE!
Things About How You Live and Would Like to Live

---

13   **How do you live now?**

Alone?
With a roommate?
 With your parents?
With other relatives?
In a group home? Other?

---

14   **What do you see as the best *things* about where you live right now?**

Jeanette said:
Having a tutor to do things with

---

15   **What do you see as the *biggest challenges* of where you live right now?**

Jeanette said:
Cleaning up the house (shares vacuuming, dusting, and other responsibilities with sister)

---

16   **What kinds of support do you need where you live right now?**

Others said:
Jeanette is fine at home, without anyone around for substantial periods of time, and can keep herself appropriately occupied. If away for a few days, mother suggests having friend over, and would not be comfortable with either daughter being home alone.

---

17   **Are you living where you want to live and with whom you want to live?**

Jeanette said:
Would like to live somewhere else, with a roommate
Doesn't know who or how Would like to live with one or two other people

If you're living where you want to live for now, please go to question #19.

---

18   **All things possible, where would you like to live and with whom?**

Jeanette said: A place that is 'affordable'
Jeanette has friend Lee Ann, who stayed over and was 'bossy' and 'nosey'[5]

Others said:
Close to friends/family

A Sample Interview

> **HOW TO GET THERE FROM HERE!**
> **Looking Ahead**

19 **What are your dreams and hopes for the future?**

Jeanette said: Not sure

20 **What scares you the most about your future?**

Jeanette said:
She can take her own meds (oral, 2x per day)

Others said:
Sister fears that if Jeanette is not more independent, she could come live with her but would likely be disgruntled
Jeanette may fear loss of health/function (e.g., some possible progressive hearing loss, etc.) Jeanette is probably fearful of not having enough money for food, etc., if she moves away from home

A Sample Interview

HOW TO GET THERE FROM HERE!
Looking Ahead

21

What do you see yourself doing in 3-5 years?

Jeanette said:
Getting a job
Leaving home
Others said:
These are the two things Jeanette talks about often

22

What support would you need to get there?

Jeanette said:
Need help from Julie at ARC-Alameda County in finding and learning a job
Regarding living on own, I need help cooking (e.g., using the oven, etc.) and how would I shop for groceries? Jeanette can shop for groceries, but would need getting groceries home. There was discussion of getting a cart, and living near a grocery store where there are curb cuts.
Others said:
Is there any way to get information and work with others to help find and develop a job for Jeanette?
Others asked Jeanette if she would need help (training/assistance) in changing sheets, getting oriented to use of public transit, getting to the doctor's office for appointments, going to places not on bus routes, doing own laundry, keeping her place clean? In many of these areas, she may need prompts or assistance.

23

Who can help you with that support? How?

Carol will look into getting Jeanette a cart to haul groceries from the store.
Susan and Karen can help by asking supervisors: "What can Jeanette work on to improve her job performance?" and asking people to be candid.
Family/friends will see about putting marks on oven dial, so that Jeanette can use oven properly. Susan would like information on conservatorship. Carolyn is seeking information/support on special needs trust, and has had person from Los Angeles
   (Estate Planning for the Disabled) out to talk about it. John Shea was asked, and agreed to share results of meeting with Julie at ABC-Long Beach, because (a)
   there may be ways to collaborate, and (b) some of the ideas/information shared might be useful to Julie.
Looking at alternative living arrangements was identified as a likely area of interest.

24

Who worked on this plan?

Susan Arnopole, mother; Carol Arnopole, sister (age 19); Virginia May, friend from church; Joy, friend and (adopted) aunt; Jenny Jackson, friend and next-door neighbor; and Karen, tutor.

Sample Plans

25 **Name of Person:** Jeanette Arnopole	**Harbor Regional Center Bringing It All Together!**	**UCI Number:**
Moving towards the future, what are some first steps that you could take over the next six months to a year?	**What kinds of support will you need from:**	
	Family, friends and community	**Support service agencies**
For fun: • Start a crafts project with sister • Learn how to type and use a computer *For Work:* Get a job *For living:* • Look at different types of places to live • Learn more about living on my own or with others *For the future:* My parents want to learn more about special needs trusts	• Go to the hobby store with my • sister to see what kind of craft might be interesting • Look at the adult education catalog to see if there are any interesting hobby or craft classes we could take together • Make an appointment at the computer center in Santa Monica • Ask Karen to go with me to try out a computer and if I'm interested in it to see what computer would be best for me • If I can't get a job right away, I'll keep volunteering at the church • Mom can help me apply to be a volunteer at the Humane • Society • Ask my sister, mom and dad or Jenny to look at different types of places to live with me • Work on a plan at home with my parents to learn more about things like cooking and shopping for groceries	• Talk with ARC/Long Beach • about supported employment • See if they can help me find • a job that's about working around people and animals • Ask the regional center for names of people and places I could look at that would give me an idea of what's out there • Ask the regional center for support in learning more about living skills that will help me be more independent, like grocery shopping and cooking • Ask ARC/Long Beach for information about special needs trusts

How will you know if your plan for the next year has worked?
- I'll be working and doing more things for fun and with my sister

Chapter 4

Sample Plans

25 **Name of Person:** John Thompson	**Harbor Regional Center Bringing It All Together!**	**UCI Number:**
Moving towards the future, what are some first steps that you could take over the next six months to a year?	**What kinds of support will you need from:**	
	Family, friends and community	**Support service agencies**
• I'll get a job • I'll be able to buy things for myself at the store	• My dad's got a friend who works at the Marriott who might be able to help me find a job • Mom and dad can help make sure I get to work • My parents can take me to the store • My day program can give me more chances to buy things in the community	• Help in interviewing for a job • Help in learning how to do the job • Help in learning how to get to and from work • Norm can assist me by calling the Department of Rehabilitation and talking to my dad about possible jobs at the Marriott • Learn how to use money at my day program

How will you know if your plan for the next year has worked?

• I'll be working Monday through Friday and making $600 a month
• I'll be able to take some of my money and buy clothes and a television

Sample Plans

25 **Name of Person:** Jessica Holmes	**Harbor Regional Center Bringing It All Together!**	**UCI Number:**
Moving towards the future, what are some first steps that you could take over the next six months to a year?	**What kinds of support will you need from:**	
	Family, friends and community	**Support service agencies**
• An after-school program • Behavior will improve	• Help from other parents to advocate for an after-school program • Cooperation from schools and child care operators to start a program • Go to a parenting class at the community college	• Advocacy from the regional center • Flexibility in using respite hours in a different way • Respite agency willing to work with a day care center to provide training and supervision • Regional center can provide respite to support our efforts at home • Regional center could provide some extra respite while we attend the college class • Regional center could provide behavior assistance to support what we learn in the class

How will you know if your plan for the next year has worked?

- We'll have an after-school program that Jessica can go to and I'll feel safe
- Her behavior will improve

Chapter 4

Circles of Support

INTRODUCTION

One of the outcomes of person-centered planning can be a circle of people who are interested in making a positive difference for and with a particular person. This group consists of the focal person and might include neighbors, friends, extended family, employers, service providers, regional center counselors, as well as any other interested persons.

CIRCLES OF SUPPORT

Although regional center counselors will not likely be active members of circles of support (most people feel that you can only fully participate in 1-2 circles), people with disabilities and their families will want more information on how to start and keep a circle going.

What are Circles-of-Support?

Around each person are people who live, work, or play with that person. Some are close relatives; some are neighbors and friends; some are paid service providers. These people—loosely or tightly, formally or informally—constitute what some call a circle-of-support. Others use the term personal team, circle-of-friends, Joshua Committee, or a similar name.

How do Circles come into existence?

There is no one way. Some individuals—because of personality, verbal skills, vulnerability, the efforts of others (e.g., parents), or for yet other reasons—have larger numbers than others of close family members and friends constructively involved in their lives.

Circles of Support

Some Circles—of widely varying sizes and degrees of organization—are put together by the individual, family, or friends, simply because of shared interests, mutual commitments and caring, and the joy of being aligned with each other. Other Circles, especially if the center of attention (often called the focus person) is a youth or adult with severe disabilities, are consciously created in an organized way.

These latter Circles may evolve from a process called personal futures planning—that is, a process known by a variety of names, in which a group of people agree to come together at least once or twice (1) to learn more about the individual and the people in that person's life; (2) to listen to that person's hopes and dreams for the future; and (3) to see what support each person may want to offer to move the focus person in the direction of a 'desired future.'

A personal team seeks to develop community connections, to invent and experiment with novel courses of action, and to stand by the person as any close friend would do. The essence of person-centered planning is having the person with a disability (along with family and friends) create a vision of a desired future, identify the support needed to get there, and determine what steps to take, here and now, in pursuit of that desired future.

Some tips on organizing and nurturing a circle-of-support:

1. Interview the focus person (and family, friends), and get names, addresses, the telephone numbers of people to invite (e.g., parents, siblings, other family, friends, neighbors, teachers or therapists, pastor, physician, etc.). Note: If the purpose of developing a circle-of-support is clear (e.g., helping the person decide where to live and with whom), be sure to invite people who can make a difference.

Chapter 4

Circles of Support

2. Set convenient time and place for initial meeting. (This should be the focus person's home or other comfortable, non-agency place.) Suggest that the focus person (or family) prepare or bring cookies, cheese and wine, or whatever.

3. Send a letter inviting people to come to an initial meeting. (See Figure A, for sample letter of invitation to first meeting.) The person with a disability may wish to follow-up by telephone.

Figure A

Friends of Bonnie Jean McLaughlin
c/o John Shea
1571 McKinley Road
Napa, CA 94558
(707) 255-5871

May 15, 1991

Bill and Gretchen Oertel
1234 Lawrence Napa, CA
94559

Dear Friends of Bonnie Jean:

Bonnie Jean has asked me to invite you to her house, 3912 Stover Street, on Monday, June 3rd, at 7:30 pm. You will be joined by several of her other friends, and family, to talk about how we can all support Bonnie. This will be a chance (1) to share with Bonnie the things that make her a friend; (2) to learn what she wants to do (and become) in the future; and (3) to 'brain-storm' how she can move toward her goals. The meeting should last for about two hours.

Bonnie Jean has asked me to help her get a circle-of-support started. No one is under any obligation to offer anything (e.g., advice, assistance, an occasional telephone call). We simply ask that everyone agree to come back at least once to see how Bonnie Jean is doing.

If you have any questions, please feel free to call me, or Bonnie Jean, or her mom and dad.
Hope to see you soon!

Cordially,

John Shea

---

4. Typical ground rules are (1) to ask people to come to first and at least one follow-up meeting; (2) no one should feel obligated to offer support (advice, information, personal assistance, etc.); and (3) keep it light and have fun.

Circles of Support

5. A facilitator should be recruited in advance, have an easel, flip-chart, marking pens, and be good at writing things down and keeping the conversation moving along. Note: If possible, someone other than a parent should do this, so that it is a community (rather than an exclusively family) affair.

6. After introductions, you can agree on additional ground rules, which might include:

• Take turns.

• Listen to one another, and probe only to clarify.

• Be respectful of each other's ideas and information.

• Keep all things [or certain things] in the room.

• If you say you will do something, follow through.

• Support one another.

7. Go through a set of questions that will provide information and direction for the future. Ask the focus person first. Then, family. Then, friends. Note what people say. Move to next question. Summarize consensus, and wrap-up with three or four 'bottom-line' questions.

8. Set date (and time) for follow-up meeting (say, in 4 weeks), write up what was learned, vision of what is wanted, steps to get there, and what people offered to do. Send out . . . , perhaps with second letter.

Circles of Support

Some lessons learned

The following factors are often critical or very important in maintaining a personal team, constructively involved in supporting the person:

1. *Communication*—One person agrees to write up the results of get-togethers, and to send out notices of upcoming get-togethers.

2. *Trust,* trying to respond to what the person wants, and consensus—Teams which listen carefully to the focus person and each other, who respect each person's views, and who base offers of assistance on what the person wants or on what the group perceives as in the person's 'best interests,' do best.

3. *Facilitation*—Someone may need to facilitate meetings, keeping track of time, identifying issues and offers of assistance, and seeing that each person has an opportunity to contribute.

4. *Having fun*—Teams whose members enjoy each other and have fun together, often stay together longer, and are eager to continue to be involved with the focus person within the context of a circle-of-support.

Circles of Support

5. *There is no single, best way*—One needs to be adaptable and responsive to the needs and desires of the focus person. One person may not like (or do well) with large, formal get-togethers. If so, try strictly social meetings. One person may wish to keep friends at some distance from one another; let this person direct the group. One person may want a full-blown personal futures plan; another may have a more limited need (e.g., to access disabled and non-disabled peers at school). The circle and its processes should reflect these differences.